

University of Dundee

A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum

Kotronoulas, Grigorios; Papadopoulou, Constantina; Burns-Cunningham, Kathryn; Simpson, Mhairi; Maguire, Roma

Published in:
European Journal of Oncology Nursing

DOI:
[10.1016/j.ejon.2017.05.004](https://doi.org/10.1016/j.ejon.2017.05.004)

Publication date:
2017

Licence:
CC BY-NC-ND

Document Version
Peer reviewed version

[Link to publication in Discovery Research Portal](#)

Citation for published version (APA):

Kotronoulas, G., Papadopoulou, C., Burns-Cunningham, K., Simpson, M., & Maguire, R. (2017). A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum. *European Journal of Oncology Nursing*, 29, 60-70. <https://doi.org/10.1016/j.ejon.2017.05.004>

General rights

Copyright and moral rights for the publications made accessible in Discovery Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from Discovery Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain.
- You may freely distribute the URL identifying the publication in the public portal.

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Manuscript Details

| | |
|--------------------------|---|
| Manuscript number | YEJON_2017_62 |
| Title | A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum |
| Article type | Review Article |

Abstract

Purpose: Gaining a clear understanding of the health needs and concerns of people with cancer of the colon and/or rectum can help identify ways to offer a comprehensive care package. Our aim was to systematically assess the relevant literature and synthesise current available evidence. Methods: A systematic review was conducted according to the PRISMA Statement guidelines. Five electronic databases were searched to identify studies employing qualitative and/or quantitative methods. Pre-specified selection criteria were applied to all retrieved records. Findings were integrated in a narrative synthesis. Results: Of 3709 references initially retrieved, 54 unique studies were retained. A total of 136 individual needs were identified and classified into eight domains. Just over half of the needs (70; 51%) concerned information/education or health system/patient-clinician communication issues. Emotional support and reassurance when trying to deal with fear of cancer recurrence featured as the most prominent need regardless of clinical stage or phase of treatment. Information about diet/nutrition and about long-term self-management of symptoms and complications at home; tackling issues relating to the quality and mode of delivery of health-related information; help with controlling fatigue; and on-going contact with a trustworthy health professional also featured as salient needs. Available research evidence is of moderate-to-good quality. Conclusions: Investing time to sensitively inquire about the supportive care needs of this patient population is key, whilst evaluating and re-shaping clinical interactions based on patients' priorities is equally essential. The diverse needs identified require a multi-professional and multi-agency approach to ensure unmet needs are addressed or measures offered.

| | |
|---|---|
| Keywords | Supportive care; Supportive care needs; Colorectal cancer; Colon cancer; Rectum cancer; Unmet needs; Patient-centred care; Patient-reported outcomes; Systematic review |
| Taxonomy | Bowel Cancer, Needs Assessment in Cancer Care |
| Corresponding Author | Grigorios Kotronoulas |
| Corresponding Author's Institution | University of Strathclyde |
| Order of Authors | Grigorios Kotronoulas, Constantina Papadopoulou, Kathryn Burns-Cunningham, Mhairi Simpson, Roma Maguire |
| Suggested reviewers | Annie Young |

Submission Files Included in this PDF

File Name [File Type]

Cover Letter EJON.docx [Cover Letter]
COI-Acknowledgements.docx [Conflict of Interest]
Response to reviewers.docx [Response to Reviewers]
Manuscript.docx [Manuscript File]
fig1new.tif [Figure]
Tables.docx [Table]
Abstract.docx [Abstract]
Highlights.docx [Highlights]
SUPPLEMENTARY MATERIAL.docx [Supporting File]
Title Page.docx [Title Page (with Author Details)]

Conflict of interest statement

The authors declare that there are no conflicts of interest in relation with this work.

Acknowledgments

We would like to thank John Connaghan, Liane Lewis, Lisa McCann, Morven Miller and Margaret Moore (Department of Computer and Information Sciences, University of Strathclyde) for their help in the data extraction process. The present work was supported through a research grant awarded by NHS Lanarkshire. The views presented in this article are those of the authors, not of the funding body.

Introduction

With an estimated 1.48 million new cases in 2015, cancer of the colon and/or rectum is the third most common cancer in the world (Ferlay et al., 2013). About 55% of cases occur in the more developed countries, but more people die (52%) in the less developed regions of the world (Ferlay et al., 2013). Recent advances in the early identification and management of cancer of the colon and/or rectum mean that the number of people surviving the disease is on the rise. Indeed, in 2017, over 3.5 million people will still be alive, five years after their diagnosis (Ferlay et al., 2013). Linked to such advances is the requirement to address the (unmet) needs for supportive care in this patient population (Ahmed et al., 2014). This is true since the diagnosis of cancer, coupled with the effects of invasive and prolonged treatments, often result in short- and long-term hardship that negatively impacts on patients and their families (Börjeson et al., 2012; Ekholm et al., 2013).

Supportive care encompasses a person-centred approach to care that aims to provide those affected by cancer with services necessary to meet their informational, emotional, social, and physical needs throughout the cancer trajectory (Hui, 2014; Rittenberg et al., 2010). Patients' expressed requirements for care that relate to the management of symptoms and side-effects, enablement of rehabilitation and coping, optimisation of understanding and informed decision-making, and minimisation of functional deficits have been defined as supportive care needs (Ream et al., 2008).

Identifying and addressing such needs is likely to prevent patient distress and morbidity (Gray et al., 2013; Grimmer et al., 2015; Ohlsson-Nevo et al., 2016; Raingruber and Bonnie, 2011; Young et al., 2010), as well as resultant increases in health care utilisation and costs (Brown et al., 2001). This seems to be of particular importance for people diagnosed with cancer of the colon and/or rectum, especially given the physical challenges/restrictions that the disease (e.g. gastrointestinal obstruction, nausea, anorexia, fatigue) and treatment (e.g. stoma care, bowel functioning, oral mucositis, neuropathy, diarrhoea) can pose in the short and long term (Glacer, 2015; Morse, 2006). Factors complicating outcomes and exacerbating needs for supportive care may include patients' older age; disease stage; comorbid illnesses; contextual, social or cultural barriers; or the lack of structured support services for cancer survivors (Glacer, 2015; Sales et al., 2014). Improving the quality of care provided to people with cancer of the colon and/or rectum requires gaining a clear understanding of their needs, taking steps to increase clinicians' awareness of such needs, and identifying innovative ways to offer a comprehensive care package (Hryniuk et al., 2014).

Our aim was to systematically assess the relevant literature and synthesise evidence in relation to the supportive care needs of people living with and beyond cancer of the colon and/or rectum. Due to the nature of the review, a modified version of the PICO (population, intervention, comparison, outcome) framework (Higgins and Green, 2011) was employed for each question, with no 'comparison' and 'intervention' replaced by 'phenomenon of interest'. We aimed to address the following research questions:

1. What unmet needs for supportive care do people diagnosed with cancer of the colon and/or rectum report?
2. What is the prevalence of unmet needs for supportive care by people diagnosed with cancer of the colon and/or rectum?
3. What role (if any) do variables, such as demographic characteristics, disease staging/location, treatment modality or time-point in cancer trajectory, seem to play in the prevalence/intensity/nature of needs for supportive care in this patient population?

Methods

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009).

Search Strategy

Five electronic databases (MEDLINE, PubMed, CINAHL, PsychINFO and EMBASE) were searched through a two-step systematic search strategy that was devised to identify studies employing qualitative and/or quantitative methods. A wide range of keywords and free text terms were used to increase inclusiveness and sensitivity of the searches (see Table S1). Utilising the PICO framework (Higgins and Green, 2011), we followed an iterative process to develop our search terms:

1. For all review questions, 'population' was defined as people diagnosed with cancer of the colon and/or rectum. The exact type of tumour location (colon or rectum) poses differences in the rates of complications, recurrence and survival (van der Sijp et al., 2016) that may impact on patients' lives

differently. However, to expand the scope of the review, we opted for inclusion of both sub-types and, where possible, aimed to offer evidence specific to the experiences of patients with one or the other tumour sub-type.

2. For all review questions there was no 'comparison'.

3. For questions one and two, the 'phenomenon of interest' was reported unmet needs for supportive care. 'Outcomes' were measures/reports of unmet needs for supportive care.

4. For question three, the 'phenomenon of interest' were measures of demographic/clinical/psychosocial variables. 'Outcomes' were measures of unmet needs for supportive care.

Pre-specified selection criteria were applied to all records identified. Reference lists of all full-text articles were also examined for any studies that might have been overlooked. Initial electronic searches were run between 20th March 2013 and 30th April 2013, and updated on 25th October 2016.

Eligibility criteria

Studies were considered for inclusion if they:

- Investigated the supportive care needs/concerns of people diagnosed with cancer of the colon and/or rectum irrespective of disease stage, treatment protocol or time-point in the illness trajectory.
- Employed quantitative and/or qualitative methods irrespective of research design.
- Were reports of primary/secondary research.
- Were published in the English language with readily available abstracts.
- Were conducted with adult (≥ 18 years of age) individuals.
- Were published as original articles in peer-reviewed journals between database inception and 2016.

Studies were excluded if they:

- Did not explicitly discuss supportive care needs/concerns of the target population, including studies reporting only on total scale scores.
- Tested the psychometric properties of supportive care needs questionnaires/measures.
- Were conducted with patients with mixed cancer diagnoses, except when separate sub-group analyses were reported.

Study Selection and Data Extraction Procedures

Three co-authors independently screened the retrieved articles for eligibility, following a two-stage process. Screening stage 1 shortlisted articles based on titles and abstracts. Stage 2 involved retrieval of articles in full-text, whereby two co-authors independently assessed all articles for eligibility against selection criteria and retained articles until consensus was reached. Data extraction tables were specifically developed for this review, pilot-tested on three randomly selected studies of the final sample, and refined accordingly. Eight researchers extracted data from the final sample of studies.

Study Methodological Quality Evaluation

The standardised QualSyst evaluation tool (Kmet et al., 2004) was used to evaluate the methodological quality of included studies. Quality was defined as the extent to which studies demonstrate internal validity according to (Kmet et al., 2004). QualSyst provides two separate scoring systems, one quantitative and one qualitative. The qualitative component comprises ten items (scored 0-2) with a maximum summary quality score of 20. The quantitative scale comprises 14 items (scored 0-2). The maximum summary quality score is 28. Summary quality scores (SQS) were reported as percentages of maximum total scores, ranging from 0 to 100%; higher SQS indicated better methodological quality. Despite the lack of formal guidelines, we considered those studies with $SQS \geq 80\%$ as the most methodologically robust. Given the lack of agreement in the application and interpretation of quality criteria (Dixon-Woods et al., 2007), no studies were excluded based on methodological quality. During data synthesis, research evidence generated by at least two studies with a median $SQS > 95\%$ was considered as high quality; a median $SQS = 90\%-95\%$ as very good quality; a median $SQS = 80\%-89\%$ as good quality; a median $SQS = 65\%-79\%$ as moderate quality; and a median $SQS = 40\%-64\%$ indicated low quality evidence. Methodological quality evaluation of the included studies was performed in parallel with data extraction.

Operational Definitions of Domains of Need

Needs were examined individually, then classified into eight theoretically/empirically/clinically-driven conceptual domains (Butow et al., 2012; Carey et al., 2012; Howell et al., 2012), namely physical/cognitive, psychosocial/emotional, family-related, social/societal, interpersonal/intimacy, practical/daily living, information/education, and health system/patient-clinician communication needs (see **Table S2** for definitions). The Supportive Care Framework (Fitch, 2008) and current definition of ‘supportive care’ (Hui, 2014) also informed this classification.

Synthesis of Study Findings

Study findings were integrated in a narrative synthesis to accommodate heterogeneity in the included studies. Information from the extraction tables was transferred onto Microsoft® Excel spread-sheets to enable description (n, %) of the characteristics of studies and samples within studies, as well as calculation of the frequency of studies (n, %) reporting on the different domains of need. Individual needs were listed and thematically aggregated by domain of need, and where available or supplied by approached study authors, within-study reported prevalence (%) of each individual need was noted. For the purposes of this review, individual needs were ranked in order of descending prevalence based on the actual number of studies reporting on each need, and secondarily based on within-study reported prevalence. Overall and domain-specific lists of individual needs were created. Across studies aggregated SQS were presented as median and range. In terms of the effects of demographic/clinical/psychosocial variables on the level of need for supportive care, meta-analysis of quantitative data was not feasible due to the heterogeneity of patient samples, methods and reporting of results. Study findings were thus integrated in a narrative synthesis.

Findings

Search Results

After initial screening of 3709 references, 131 potentially eligible articles were retained and retrieved in full-text. Another 21 articles were identified through reference lists of electronically identified articles, for a total of 152 full-text articles. Of these, 98 were excluded due to various reasons (**Figure 1**). Fifty-four studies (Anderson et al., 2013; Andersson et al., 2010; Bain and Campbell, 2000; Bain et al., 2002; Baravelli et al., 2009; Beaver et al., 2010, 1999; Beckjord et al., 2008; Boudioni et al., 2001; Browne et al., 2011; Carlsson et al., 2010; Cha et al., 2012; Di Fabio et al., 2008; Dunn et al., 2006; Galloway and Graydon, 1996; Hansen et al., 2013; Harrison et al., 2011; Ho et al., 2016; Holm et al., 2012; Husson, 2013; Jefford et al., 2011; Jorgensen et al., 2012; Kidd, 2014; Klemm et al., 2000; Knowles et al., 1999; Lam et al., 2016; Landers et al., 2014; Li et al., 2012; Lithner et al., 2015, 2012; Macvean et al., 2007; McCaughan et al., 2012; Morrison et al., 2012; Nikoletti et al., 2008; Northouse et al., 1999; Papagrigoriadis and Heyman, 2003; Pullar et al., 2012; Ran et al., 2016; Rozmovits et al., 2004; Russell et al., 2015; Sahay and Gray, 2000; Salamonsen et al., 2016; Salkeld et al., 2004; Salz et al., 2014; Sanoff et al., 2010; Santin et al., 2015; Shun et al., 2014; Sjövall et al., 2011; Taylor et al., 2012; Traa et al., 2014; Walling et al., 2016; Wiljer et al., 2013; Worster and Holmes, 2008; Zullig et al., 2012) met eligibility criteria and were considered for further analysis.

Study Characteristics and Methodological Quality

All studies were descriptive and observational; 12 (22%) collected data at multiple time-points (see **Table S3**). Thirty-two (59%) studies employed quantitative methods only, 18 qualitative methods only, while four were mixed-methods studies (7%). Studies were predominantly single-centred (27; 50%), although a sizable number (17; 32%) were multi-centre studies. Five community-based and five population-based studies were also included.

Studies varied in methodological quality with SQS ranging from 44% to 95%, with a median SQS of 80%. Over half studies (29; 54%) had SQS \geq 80%. Across those studies employing quantitative methods (median SQS=82%; range=44%-95%; 21/36 studies with SQS \geq 80%), areas of strength included the use of well-defined/robust outcome measures, detailed discussion of data analysis and findings, and conclusions that were clearly linked to findings. Lower scores were received in relation to a sampling technique that could result in a biased sample, participant characteristics insufficiently described, and inappropriate sample sizes. Across studies employing qualitative methods (median SQS=75%; range=60%-90%; 9/22 studies with SQS \geq 80%), areas of weakness

included sampling strategy insufficiently described, unclear data analysis procedures, lack of verification procedures for credibility, and insufficient information reflexivity of the account.

Study sample sizes varied widely among the studies, ranging from 5 to 3011 people with cancer of the colon and/or rectum (overall median 50; quantitative methods median 113; qualitative methods median 23; mixed-methods median 21), representing 10,057 participants in total. In terms of origin, there were 28 European, 11 North American, 11 Oceanian and 4 Asian studies. Studies were predominantly conducted in the UK (16; 30%) and Australia (9; 17%). Twenty-seven articles (50%) were published in the past five years (2012-2016); 40 articles (74%) were published in the last decade (2007-2016). Only four articles (7%) were published before 2000.

Characteristics of the Study Samples

Within-study age-means/medians ranged from 51.9 to 72 years, with 31 studies including samples with a mean/median age of ≥ 60 years. Available data indicated that 64.5% (3522/5464) of participants were men; 74% (1567/2119) were married; 68% (1927/2824) had at least secondary education; and 27% (813/2980) were employed. Across studies, time since cancer diagnosis ranged from <3 months to 7 years prior to study participation. Where reported, 31% of participants were diagnosed with stage II cancer (1175/3772), 32% with stage III cancer (1193/3772) and 10% with metastatic cancer (381/3912). In terms of tumour site, 56.5% (1083/1916) of cases corresponded to cancers of the colon; 41% (793/1926) were cancers of the rectum. From available data, 97% (3412/3502) of participants underwent surgery, 26% (620/2408) received radiotherapy and 44% (1116/2527) received chemotherapy. Where reported, 30% (518/1747) had a stoma.

Seventeen studies focused on the post-treatment period only (Anderson et al., 2013; Baravelli et al., 2009; Beaver et al., 2010; Beckjord et al., 2008; Di Fabio et al., 2008; Ho et al., 2016; Holm et al., 2012; Husson, 2013; Jefford et al., 2011; Klemm et al., 2000; McCaughan et al., 2012; Morrison et al., 2012; Russell et al., 2015; Salkeld et al., 2004; Salz et al., 2014; Santin et al., 2015; Taylor et al., 2012), 13 studies focused on the post-operative period only (Andersson et al., 2010; Browne et al., 2011; Cha et al., 2012; Galloway and Graydon, 1996; Harrison et al., 2011; Jorgensen et al., 2012; Lithner et al., 2015, 2012; Nikoletti et al., 2008; Northouse et al., 1999; Ran et al., 2016; Salamonsen et al., 2016; Sanoff et al., 2010), 2 studies examined the transition from the pre-operative to the post-operative period (Carlsson et al., 2010; Worster and Holmes, 2008), whilst 2 studies specifically explored needs during curative (Kidd, 2014) and during palliative treatment (Sjövall et al., 2011). The remaining 19 studies relied on mixed samples of patients, who were at different treatment phases.

Supportive Care Needs in People with Colorectal Cancer

A total of 136 individual needs were reported across the reviewed studies. Just over half of these needs (70; 51%) concerned information/education (36; 26.5%) or health system/patient-clinician communication issues (34; 25%) (Table S2).

Top Ten Most Prominent Individual Needs

Ten individual needs featured as most prominent based on frequency of reporting within and across the reviewed studies. Relevant research evidence was of moderate-to-good quality (Table 1). Five needs were classified as patient information/education, whilst three needs pertained health system/patient-clinician communication. The need for emotional support and reassurance when trying to deal with fear of the cancer returning or spreading featured at the very top of the list. This was followed by the need for more information about diet/nutrition (#2) and long-term self-management of symptoms and complications at home (#3). Issues relating to the quality and mode of delivery of health-related information featured at #4 and #5. Additional information needs, help with controlling fatigue, and need for on-going contact with a trustworthy health professional were placed between #6 and #10.

Top Needs per Domain of Need

Five needs featured prominently in the physical/cognitive domain (Table S2a; median SQS=75%; range=44%-91%; 7/17 studies with SQS \geq 80%). These included fatigue/lack of energy, abdominal pain, defecation problems, digestive dysfunction, and sleep loss. Pain, fatigue and sleep loss were particularly troubling issues in the post-operative period.

There were also five main needs featuring in the psychosocial/emotional needs domain. These were emotional support and reassurance when dealing with fear of the cancer spreading or returning, support when dealing with uncertainty about the future, support to come to terms with the diagnosis and deal with feelings of shock and ‘mental isolation’, psychological support with feelings of abandonment after treatment completion, and support with concerns about being a burden for or dependent on others (Table S2b; median SQS=75%; range=44%-91%; 11/25 studies with SQS≥80%).

In the family-related domain, the three most salient needs were support of the family (especially children) with their own worries/concerns, support of the patient with his/her own concerns about the family’s future, and help with the informational needs of the family (Table S2c; median SQS=80%; range=44%-90%; 5/9 studies with SQS≥80%).

Accessing support groups for survivors was the most prominent social/societal need (Table S2d; median SQS=80%; range=72%-90%; 5/7 studies with SQS≥80%). A need for help to avoid stoma-related embarrassment in social situations (#2) by knowing the proximity/location of a toilet (#3) and by planning ahead for social events (#4) was also reported.

Predominant needs in the interpersonal/intimacy domain were the need for help to adjust to changes in sexuality, deal with an altered body image, and manage concerns about sexual dysfunction (Table S2e; median SQS=80%; range=44%-91%; 8/15 studies with SQS≥80%).

Twelve unique practical/daily living needs were identified (Table S2f; median SQS=80%; range=46%-94%; 13/21 studies with SQS≥80%). Most prominently, patients expressed a need for help to adjust with the restrictions posed by the surgical/systemic treatment of colorectal cancer and its side-effects. Transportation and access issues, financial and work-related issues, as well as difficulties establishing dietary changes were also reported as triggers of need for support.

In addition to the five information/education needs reported in the Top Ten Most Prominent Individual Needs section, a wealth of information needs around the exact diagnosis, test results, cancer treatment options (peri-/post-diagnostic period), treatment side-effects (active treatment period), and what to expect in the post-treatment/discharge period were reported (Table S2g; median SQS=80%; range=44%-95%; 21/38 studies with SQS≥80%).

Prominent health system/patient-clinician communication needs included not only the quality and delivery of information or on-going patient-clinician contact, but also to the qualities of a caring health professional and to better coordination of primary and secondary health care services. Notably, patients expressed the need for post-operative follow-up by a hospital doctor, but overall post-treatment follow-up by a specialist nurse (Table S2h; median SQS=80%; range=60%-95%; 21/36 studies with SQS≥80%).

Potential Correlates of Supportive Care Needs

Over twenty demographic, clinical and psychosocial covariates were tested for their effects on the nature, prevalence and intensity of supportive care needs in the studies reviewed. Wide diversity in the associations between these covariates and various expressed needs was noted (Table 2). Female gender (median SQS=87%; range=73%-95%; 4/6 studies with SQS≥80%) and younger age (median SQS=82%; range=61%-86%; 4/6 studies with SQS≥80%) were the most consistent predictors of unaddressed concerns, greater need for support and greater need for shared decision-making across different study contexts.

Nine clinical factors were associated with increased physical needs (recent treatment, rectal cancer diagnosis, presence of stoma, late stage disease), increased information and patient-clinician communication needs (overweight/obese status, poorer pre-operative health status, rectal cancer diagnosis), increased social needs (recent treatment, more bowel symptoms, shorter symptom duration), increased psychological needs (presence of stoma) and/or increased practical/daily living needs (presence of uncontrolled pain).

In terms of psychosocial covariates, negative perceptions about the illness and the effectiveness of treatment, uncertainty, symptom distress, cancer-related rumination, depression, and type D personality (“distressed personality”) were invariably linked to a greater need for support, help with physical symptoms, and provision of information.

Discussion

Summary and Critique of Evidence

Cancer of the colon and/or rectum remains a global health issue. Early detection has been linked to timely curative treatment and decreased morbidity. However in clinical practice, people with cancer of the colon and/or rectum still present with an array of needs and concerns. Indeed, our systematic review revealed 136 unique supportive care needs based on moderate-to-good quality research evidence. Individual needs were classified into eight broad domains; half of these needs were related to information provision and patient-clinician communication. Diversity in the demographic and clinical characteristics of the study samples enabled an exploration of the needs of this patient population as a whole. Emotional support and reassurance (especially when dealing with fear of cancer recurrence), more information and better patient education, and better interaction with the healthcare system were the most prominent needs overall.

The psychological impact of living with cancer primarily manifests itself in a pervasive need to deal with fear of cancer recurrence. As with other cancer patient populations, we found moderate-to-good quality research evidence, indicating the number one need of people with cancer of the colon and/or rectum to be emotional support and reassurance (up to 3 out of 10 patients), especially concerning cancer recurrence (up to 6 to 10 patients). This was coupled by a need for more information about the risk of recurrence and/or symptoms of recurrence (good quality research evidence) featuring high in the top ten most prominent needs. Fear of cancer recurrence has been shown to persist over an extensive period of time post-diagnosis, adversely affecting quality of life and emotional well-being (Koch et al., 2013). A few promising psycho-educational interventions have been tested thus far (Ohlsson-Nevo et al., 2016; Simard et al., 2013), the effectiveness of which is yet to be established. Averyt and Nishimoto (2014) provide clinicians with a crib-sheet of answers to questions that patients who enter survivorship may have when dealing with the above psychosocial/information issues around cancer of the colon and/or rectum.

Similar to other cancer patient populations (Fiszer et al., 2014; Hall et al., 2013; Harrison et al., 2009; Maguire et al., 2015, 2013), the need of people with cancer of the colon and/or rectum for an increasing amount of tailored information became apparent in our findings, based good quality research evidence overall. Despite some moderate quality research evidence, 15 of the included studies revealed that between 46% and 98% of people with cancer of the colon and/or rectum require more information about diet and nutrition. Dietary changes are prescribed as a necessary adjunct to effective treatment and long-term adjustment, but clearly information provision has not reached optimal levels. The same is true for comprehensive information on the long-term self-management of symptoms and complications at home (good quality research evidence). Today, self-management is considered a vital component of care. Improving the skills of patients and families to self-manage unsupervised at home has been the target of recent interventions (Gray et al., 2013; Young et al., 2010), but the real challenge remains to integrate systematic self-care training and information provision into every day clinical practice. The diverse needs identified in this specific domain require a multi-professional and multi-agency approach to ensure unmet information/education needs are addressed or measures offered. Multidisciplinary teams (MDTs) across the world could co-ordinate information by identifying/preparing key members to act as 'information/education champions', who can either provide information/education themselves or signpost to the right avenue.

Linked to the provision of information is effective patient-clinician communication, with high quality interactions and service being essential. Good quality research evidence suggests that people with cancer of the colon and/or rectum do not just need an effective (e.g. written v. oral) and on-going mode of information delivery. They also want to experience unhurried, sensitive and honest patient-clinician interactions that are based on the exchange of straightforward and personalised information. There is no doubt that MDTs strive for excellence when offering care to their patients, but, as shown in this review, the high rates of patients endorsing the need for better interaction with the healthcare system is a clear message for improvement. Better coordination among healthcare professionals also is key, especially as patients transition from acute to rehabilitation care and primary care/community service providers take over from secondary care. Current health system challenges coupled with an influx of people seeking care for cancer of the colon and/or rectum render additional effort for quality care, possibly backed up by utilisation of community resources (voluntary and third sector) and/or telehealth solutions (Cox et al., 2017), all the more important.

Of note, our review indicated that the need for adequate patient information/education/navigation/sign-posting and effective patient-clinician communication was central to all other domains identified. That said, it is interesting that information and communication are currently categorised in supportive care frameworks/definitions (Fitch, 2008; Hui, 2014) as distinct domains, akin to physical, emotional, psychological,

social and spiritual aspects of care. We recognise that theoretical frameworks, such as the most widely used Supportive Care Framework (Fitch, 2008), serve as guiding tools for cancer care professionals and managers to understand what type of help patients might need and plan service delivery accordingly. Yet, we urge health professionals to consider patient information, education and communication as universal aspects of care that guide good practice relating to all domains of supportive care.

The need for help with on-going symptom control became apparent in our sample of studies. Despite some moderate quality research evidence, for seasoned MDT members, it must be hardly surprising that fatigue, pain, defecation and digestive issues were prominent issues (up to 3 out of 10 patients in need), especially in the post-operative period (Börjeson et al., 2012). Yet, fatigue still featured as one of the ten most prominent needs in this patient population, which is a clear indication for more focussed and ongoing intervention. Of note, the expressed need for insomnia counter-measures (3 out of 10 patients in need) may be a new area for intervention with patients with cancer of the colon and/or rectum. Insomnia symptoms remain under-reported, under-assessed and under-managed in the context of cancer (Lowery, 2014). Systematic assessment coupled with access to cognitive-behavioural treatment is therefore warranted (Howell et al., 2014; Lowery, 2014).

Our review can act as a valuable educational toolkit for junior and senior MDT members, who provide care to people with cancer of the colon and/or rectum. Not only did we establish the most prominent supportive care needs in this patient population, but we also identified those less ‘visible’ or expressed less often. Need for help with cognitive alterations, management of comorbidities, concerns about dependency on others, fear of loss of bowel control, concerns about the family’s future, altered body image and sexuality, adjusting to the daily restrictions posed by altered bowel function or stoma, accessing support groups, and performing wound/stoma care were but a few. Perhaps, the quality of current research evidence is predominantly moderate, but for certain needs (e.g. help with the concerns of one’s family/children; help with social embarrassment/loss of dignity; help with transportation and access barriers; support with finances/work; self-management; access to professional counselling) more reliable evidence does exist. Systematic needs assessments, possibly via use of (electronic) patient-reported outcome (PRO) measures (Basch, 2016; Cox et al., 2017), can promote person-centred care and enable timely management of priority issues to reduce distress (Howell et al., 2015). With current research supporting the use of PRO measures in routine clinical practice (Kotronoulas et al., 2014), inclusion of appropriate and adequate measures of need is essential.

Heterogeneity in our sample of studies revealed a number of gaps in current methodology. First, evidence is skewed towards patients with non-metastatic cancers. As a result, the needs of those with metastatic disease are not truly reflected. Advanced cancer can be predictive of more physical, psychological, information and practical supportive care needs and increased psychological distress (Vodermaier et al., 2011). Second, despite the range of potential correlates, predictors of unmet need in this population remain fairly under-researched. Relying on good quality research evidence, younger age and female gender are consistently linked to greater unmet need. The underlying reasons can only be presumed, but the requirement for extra attention to these two patient sub-groups is evident, especially in light of recent evidence revealing a sharp rise in rates of cancer of the colon and/or rectum among young adults (Bailey et al., 2015; Gordon, 2016). In contrast, evidence on other demographic, clinical or psycho-social variables is either mixed (e.g. education attainment) or predominantly derives from unreplicated single studies only. Until new evidence emerges, the suggested relationships can nevertheless raise clinician awareness on potential areas for intervention. Last, only a small number of longitudinal studies exist, therefore fluctuations (or lack of) in patients’ needs from the pre- to post-operative and then to post-treatment and survivorship period remain largely unknown.

Review Strengths and Limitations

We followed a strict systematic approach to identify and select all studies that met our eligibility criteria, assess their methodological quality, and synthesise evidence in accordance to PRISMA guidelines (Moher et al., 2009). We endeavoured to enrich our dataset by contacting study authors for any missing information or for clarification of study findings. Our synthesis of evidence was conducted in an unbiased manner to promote reproducibility. Some limitations of our sample of studies and review methodology must be acknowledged. Mixed patient samples recruited in the greatest majority of studies we reviewed (often under the umbrella term ‘colorectal cancer’) prevented distinction in patients’ needs for supportive care based on tumour sub-type. We opted for an inclusive search strategy, but this was not exhaustive as it was limited to the most common databases. Due to time constraints, we excluded grey literature, thus focussing on peer-reviewed articles only. We further limited our search to English language publications only. We cannot rule out the possibility that studies published in languages other than English might have been missed, but we anticipate that the number of these to be minimal. Last, the

QualSyst evaluation tool (Kmet et al., 2004) was used to appraise the methodological quality studies with diverse study designs. Although the tool allows across-study comparisons based on higher quality scores, no guidelines are provided as to which scores are indicative of good levels of internal validity. We provided summaries of the strength of evidence based on QualSyst summary quality scores, but did not use a more formal evaluation technique, such as the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) framework (Schünemann et al., 2013).

Conclusions

Regardless of disease type or stage, people with cancer of the colon and/or rectum may struggle to adapt to their illness, cope with treatment and adjust to their new life situation. Succeeding in this may depend on the extent to which their supportive care needs are met. Current moderate-to-good quality research evidence suggests an array of physical, emotional, family-related, social, intimacy and practical supportive care needs for people with cancer of the colon and/or rectum in addition to universal and cancer-specific information/education and communication needs. Of all reported needs, cancer recurrence, lack of information and health system inconsistencies appear to be the most distressing issues. Such concerns may generate needs that may be unique in their frequency and/or intensity, possibly moderated by this patient population's characteristics and/or circumstances. The importance of investing time to sensitively inquire about the supportive care needs of people with cancer of the colon and/or rectum is a key message for all clinicians that provide care to this patient population irrespective healthcare sector (Jones et al., 2011). This would assist with evaluating and re-shaping clinical interactions so that they are based on patients' priorities and needs. Clinicians are urged to use findings of this review in their everyday interactions with people with cancer of the colon and/or rectum to identify their priorities in relation to needs and concerns to facilitate safe, effective and person-centred care.

Conflict of interest statement

The authors declare that there are no conflicts of interest in relation with this work.

Acknowledgments

We would like to thank John Connaghan, Liane Lewis, Lisa McCann, Morven Miller and Margaret Moore (Department of Computer and Information Sciences, University of Strathclyde) for their help in the data extraction process. The present work was supported through a research grant awarded by NHS Lanarkshire. The views presented in this article are those of the authors, not of the funding body.

Figure legends

Figure 1. CONSORT diagram of the article selection process.

Table legends

Table 1. Top twenty (top ten in shaded section) most prominent individual needs for people with cancer of the colon and/or rectum based on frequency of reporting within and across the reviewed studies

Table 2. Correlates of supportive care needs in people with cancer of the colon and/or rectum across the reviewed studies

Table S1. Electronic databases searched and search terms used

Table S2. Individual supportive care needs of people with cancer classified into need domains and ranked for prominence within each need domain

Table S3. Summaries of the 54 articles reviewed.

References

- Ahmed, N., Ahmedzai, S., Collins, K., Noble, B., 2014. Holistic assessment of supportive and palliative care needs: the evidence for routine systematic questioning. *BMJ Support. Palliat. Care* 1–9. doi:10.1136/bmjspcare-2012-000324
- Anderson, A.S., Steele, R., Coyle, J., 2013. Lifestyle issues for colorectal cancer survivors - Perceived needs, beliefs and opportunities. *Support. Care Cancer* 21, 35–42. doi:10.1007/s00520-012-1487-7
- Andersson, G., Engström, Å., Söderberg, S., 2010. A chance to live: Women's experiences of living with a colostomy after rectal cancer surgery. *Int. J. Nurs. Pract.* 16, 603–608. doi:10.1111/j.1440-172X.2010.01887.x
- Averyt, J.C., Nishimoto, P.W., 2014. Psychosocial issues in colorectal cancer survivorship: The top ten questions patients may not be asking. *J. Gastrointest. Oncol.* doi:10.3978/j.issn.2078-6891.2014.058
- Bailey, C.E., Hu, C.-Y., You, Y.N., Bednarski, B.K., Rodriguez-Bigas, M.A., Skibber, J.M., Cantor, S.B., Chang, G.J., 2015. Increasing disparities in the age-related incidences of colon and rectal cancers in the United States, 1975-2010. *JAMA Surg.* 150, 17–22. doi:10.1001/jamasurg.2014.1756
- Bain, N.S., Campbell, N.C., 2000. Treating patients with colorectal cancer in rural and urban areas: a qualitative study of the patients' perspective. *Fam. Pract.* 17, 475–479.
- Bain, N.S.C., Campbell, N.C., Ritchie, L.D., Cassidy, J., 2002. Striking the right balance in colorectal cancer care—a qualitative study of rural and urban patients. *Fam. Pract.* 19, 369–74.
- Baravelli, C., Krishnasamy, M., Pezaro, C., Schofield, P., Lotfi-Jam, K., Rogers, M., Milne, D., Aranda, S., King, D., Shaw, B., Grogan, S., Jefford, M., 2009. The views of bowel cancer survivors and health care professionals regarding survivorship care plans and post treatment follow up. *J. Cancer Surviv.* 3, 99–108. doi:10.1007/s11764-009-0086-1
- Basch, E., 2016. The Rise of Patient-Reported Outcomes in Oncology | ASCO Annual Meeting [WWW Document]. *Am. Soc. Clin. Oncol.* URL <https://am.asco.org/daily-news/rise-patient-reported-outcomes-oncology> (accessed 2.16.17).
- Beaver, K., Janet Bogg, C., Luker, K.A., 1999. Decision-making role preferences and information needs: A comparison of colorectal and breast cancer. *Heal. Expect.* 2, 266–276. doi:10.1046/j.1369-6513.1999.00066.x
- Beaver, K., Latif, S., Williamson, S., Procter, D., Sheridan, J., Heath, J., Susnerwala, S., Luker, K., 2010. An exploratory study of the follow-up care needs of patients treated for colorectal cancer. *J. Clin. Nurs.* 19, 3291–3300. doi:10.1111/j.1365-2702.2010.03407.x
- Beckjord, E.B., Arora, N.K., McLaughlin, W., Oakley-Girvan, I., Hamilton, A.S., Hesse, B.W., 2008. Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. *J Cancer Surviv* 2, 179–189. doi:10.1007/s11764-008-0055-0
- Börjeson, S., Starkhammar, H., Unosson, M., Berterö, C., 2012. Common Symptoms and Distress Experienced Among Patients with Colorectal Cancer: A Qualitative part of Mixed Method Design. *Open Nurs. J.* 6, 100–7. doi:10.2174/1874434601206010100
- Boudioni, M., McPherson, K., Moynihan, C., Melia, J., Boulton, M., Leydon, G., Mossman, J., 2001. Do men with prostate or colorectal cancer seek different information and support from women with cancer? *Br. J. Cancer* 85, 641–8. doi:10.1054/bjoc.2001.1945
- Brown, M.L., Lipscomb, J., Snyder, C., 2001. The burden of illness of cancer: economic cost and quality of life. *Annu Rev Public Heal.* 22, 91–113.
- Browne, S., Dowie, A., Mitchell, L., Wyke, S., Ziebland, S., Campbell, N., Macleod, U., 2011. Patients' needs following colorectal cancer diagnosis: Where does primary care fit in? *Br. J. Gen. Pract.* 61, 692–699. doi:10.3399/bjgp11X606582
- Butow, P.N., Phillips, F., Schweder, J., White, K., Underhill, C., Goldstein, D., 2012. Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: A systematic review. *Support. Care Cancer.* doi:10.1007/s00520-011-1270-1
- Carey, M., Lambert, S., Smits, R., Paul, C., Sanson-Fisher, R., Clinton-Mcharg, T., 2012. The unfulfilled promise: A systematic review of interventions to reduce the unmet supportive care needs of cancer patients. *Support. Care Cancer* 20, 207–219. doi:http://dx.doi.org/10.1007/s00520-011-1327-1
- Carlsson, E., Berndtsson, I., Hallén, A.-M., Lindholm, E., Persson, E., 2010. Concerns and quality of life before surgery and during the recovery period in patients with rectal cancer and an ostomy. *J. Wound. Ostomy Continence Nurs.* 37, 654–661. doi:10.1097/WON.0b013e3181f90f0c
- Cha, R., Murray, M.J., Thompson, J., Wall, C.R., Hill, A., Hulme-Moir, M., Merrie, A., Findlay, M.P.N., 2012. Dietary patterns and information needs of colorectal cancer patients post-surgery in Auckland. *N. Z. Med. J.* 125, 38–46.
- Cox, A., Lucas, G., Marcu, A., Piano, M., Grosvenor, W., Mold, F., Maguire, R., Ream, E., 2017. Cancer Survivors' Experience With Telehealth: A Systematic Review and Thematic Synthesis. *J. Med. Internet Res.* 19, e11. doi:10.2196/jmir.6575

- Di Fabio, F., Koller, M., Nascimbeni, R., Talarico, C., Salerni, B., 2008. Long time outcome after colorectal cancer resection. Patients' self-reported quality of life, sexual dysfunction and surgeons' awareness of patients' needs. *Tumori* 94, 30–35.
- Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S., Booth, A., Jones, D., 2007. Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *J Heal. Serv Res Policy* 12, 42–47. %U <http://jhsrps.rsmjournals.com/cgi/content/doi:10.1258/135581907779497486>
- Dunn, J., Lynch, B., Rinaldis, M., Pakenham, K., McPherson, L., Owen, N., Leggett, B., Newman, B., Aitken, J., 2006. Dimensions of quality of life and psychosocial variables most salient to colorectal cancer patients. *Psychooncology* 15, 20–30. doi:10.1002/pon.919
- Ekholm, K., Grönberg, C., Börjeson, S., Berterö, C., 2013. The next of kin experiences of symptoms and distress among patients with colorectal cancer: Diagnosis and treatment affecting the life situation. *Eur. J. Oncol. Nurs.* 17, 125–130. doi:10.1016/j.ejon.2012.05.003
- Ferlay, J., Soerjomataram, I., Ervik, M., Dikshit, R., Eser, S., Mathers, C., Rebelo, M., Parkin, D.M., Forman, D., Bray, F., 2013. GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11 [WWW Document]. Int. Agency Res. Cancer, Lyon. URL <http://globocan.iarc.fr/Default.aspx> (accessed 5.19.16).
- Fiszer, C., Dolbeault, S., Sultan, S., Br??dart, A., 2014. Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: A systematic review. *Psychooncology*. doi:10.1002/pon.3432
- Fitch, M.I., 2008. Supportive care framework. *Can. Oncol. Nurs. J.* 18, 6–24. doi:10.5737/1181912x181614
- Galloway, S.C., Graydon, J.E., 1996. Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. *Cancer Nurs.* 19, 112–117. doi:10.1097/00002820-199604000-00005
- Glacer, A., 2015. Quality of Life of Colorectal Cancer Survivors in England: Report on a national survey of colorectal cancer survivors using Patient Reported Outcome Measures (PROMs) [WWW Document]. NHS Engl. Publ. Gatew. URL <https://www.england.nhs.uk/wp-content/uploads/2015/03/colorectal-cancer-proms-report-140314.pdf> (accessed 11.4.16).
- Gordon, C., 2016. Why Is Colorectal Cancer Targeting the Young? [WWW Document]. Medscape. URL <http://www.medscape.com/viewarticle/857294> (accessed 3.7.17).
- Gray, N.M., Allan, J.L., Murchie, P., Browne, S., Hall, S., Hubbard, G., Johnston, M., Lee, A.J., McKinley, A., Macleod, U., Presseau, J., Samuel, L., Wyke, S., Campbell, N.C., 2013. Developing a community-based intervention to improve quality of life in people with colorectal cancer: a complex intervention development study. *BMJ Open* 3, 10.1136/bmjopen-2013-002596. Print 2013. doi:10.1136/bmjopen-2013-002596 [doi]
- Grimmett, C., Simon, A., Lawson, V., Wardle, J., 2015. Diet and physical activity intervention in colorectal cancer survivors: A feasibility study. *Eur. J. Oncol. Nurs.* 19, 1–6. doi:10.1016/j.ejon.2014.08.006
- Hall, A., Lynagh, M., Bryant, J., Sanson-Fisher, R., 2013. Supportive care needs of hematological cancer survivors: A critical review of the literature. *Crit. Rev. Oncol. Hematol.* doi:10.1016/j.critrevonc.2013.03.008
- Hansen, D.G., Larsen, P.V., Holm, L.V., Rottmann, N., Bergholdt, S.H., Søndergaard, J., 2013. Association between unmet needs and quality of life of cancer patients: a population-based study. *Acta Oncol.* 52, 391–9. doi:10.3109/0284186X.2012.742204
- Harrison, J.D., Young, J.M., Auld, S., Masya, L., Solomon, M.J., Butow, P.N., 2011. Quantifying postdischarge unmet supportive care needs of people with colorectal cancer: A clinical audit. *Color. Dis.* 13, 1400–1406. doi:10.1111/j.1463-1318.2010.02478.x
- Harrison, J.D., Young, J.M., Price, M.A., Butow, P.N., Solomon, M.J., 2009. What are the unmet supportive care needs of people with cancer? A systematic review. *Support. Care Cancer* 17, 1117–1128. doi:10.1007/s00520-009-0615-5
- Higgins, J., Green, S., 2011. Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]. Cochrane Collab. 0, 10–11.
- Ho, M.Y., McBride, M.L., Gotay, C., Grunfeld, E., Earle, C.C., Relova, S., Tsonis, M., Ruan, J.Y., Chang, J.T., Cheung, W.Y., 2016. A qualitative focus group study to identify the needs of survivors of stage II and III colorectal cancer. *Psychooncology* 25, 1470–1476. doi:10.1002/pon.3988
- Holm, L.V., Hansen, D.G., Johansen, C., Vedsted, P., Larsen, P.V., Kragstrup, J., Søndergaard, J., 2012. Participation in cancer rehabilitation and unmet needs: A population-based cohort study. *Support. Care Cancer* 20, 2913–2924. doi:10.1007/s00520-012-1420-0
- Howell, D., Mayo, S., Currie, S., Jones, G., Boyle, M., Hack, T., Green, E., Hoffman, L., Collacutt, V., McLeod, D., Simpson, J., 2012. Psychosocial health care needs assessment of adult cancer patients: a consensus-based guideline. *Support. Care Cancer* 20, 3343–54. doi:10.1007/s00520-012-1468-x
- Howell, D., Molloy, S., Wilkinson, K., Green, E., Orchard, K., Wang, K., Liberty, J., 2015. Patient-reported outcomes in routine cancer clinical practice: a scoping review of use, impact on health outcomes, and

- implementation factors. *Ann. Oncol.* 26, 1846–1858. doi:10.1093/annonc/mdv181
- Howell, D., Oliver, T.K., Davidson, J.R., Garland, S., Samuels, C., Savard, J., Harris, C., Aubin, M., Olson, K., Sussman, J., Macfarlane, J., Taylor, C., Keller-Olaman, S., Davidson, J.R., Garland, S., Samuels, C., Savard, J., Harris, C., Aubin, M., Olson, K., Sussman, J., Macfarlane, J., Taylor, C., 2014. Sleep disturbance in adults with cancer: a systematic review of evidence for best practices in assessment and management for clinical practice. *Ann. Oncol.* 25, 791–800. doi:10.1093/annonc/mdt506
- Hryniuk, W., Simpson, R., McGowan, A., Carter, P., 2014. Patient perceptions of a comprehensive cancer navigation service. *Curr. Oncol.* 21, 69. doi:10.3747/co.21.1930
- Hui, D., 2014. Definition of supportive care: does the semantic matter? *Curr. Opin. Oncol.* 26, 372–9. doi:10.1097/CCO.0000000000000086
- Husson, O., 2013. Information provision and patient reported outcomes in cancer survivors: with a special focus on thyroid cancer [WWW Document]. Ridderkerk: Ridderprint. URL https://pure.uvt.nl/ws/files/1493427/Husson_information_01-03-2013.pdf (accessed 4.14.16).
- Jefford, M., Lotfi-Jam, K., Baravelli, C., Grogan, S., Rogers, M., Krishnasamy, M., Pezaro, C., Milne, D., Aranda, S., King, D., Shaw, B., Schofield, P., 2011. Development and pilot testing of a nurse-led posttreatment support package for bowel cancer survivors. *Cancer Nurs.* 34, E1–E10. doi:10.1097/NCC.0b013e3181f22f02
- Jones, R., Regan, M., Ristevski, E., Breen, S., 2011. Patients' perception of communication with clinicians during screening and discussion of cancer supportive care needs. *Patient Educ. Couns.* 85. doi:10.1016/j.pec.2010.12.006
- Jorgensen, M.L., Young, J.M., Harrison, J.D., Solomon, M.J., 2012. Unmet supportive care needs in colorectal cancer: Differences by age. *Support. Care Cancer* 20, 1275–1281. doi:10.1007/s00520-011-1214-9
- Kidd, L.A., 2014. Consequences, control and appraisal: cues and barriers to engaging in self-management among people affected by colorectal cancer - a secondary analysis of qualitative data. *Heal. Expect.* 17, 565–578. doi:10.1111/j.1369-7625.2012.00785.x
- Klemm, P., Miller, M.A., Fernsler, J., 2000. Demands of illness in people treated for colorectal cancer. *Oncol. Nurs. Forum* 27, 633–639.
- Kmet, L., Lee, R., Cook, L., 2004. Standard quality assessment criteria for evaluating primary research papers from a variety of fields [WWW Document]. Alberta Herit. Found. Med. Res. URL <http://www.biomedcentral.com/content/supplementary/1471-2393-14-52-s2.pdf> (accessed 4.14.16).
- Knowles, G., Tierney, A., Jodrell, D., Cull, A., 1999. The perceived information needs of patients receiving adjuvant chemotherapy for surgically resected colorectal cancer. *Eur. J. Oncol. Nurs.* 3, 208–220. doi:http://dx.doi.org/10.1016/S1462-3889(99)81332-5
- Koch, L., Jansen, L., Brenner, H., Arndt, V., 2013. Fear of recurrence and disease progression in long-term (≥ 5 years) cancer survivors—a systematic review of quantitative studies. *Psychooncology.* 22, 1–11. doi:10.1002/pon
- Kotronoulas, G., Kearney, N., Maguire, R., Harrow, A., Di Domenico, D., Croy, S., MacGillivray, S., 2014. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J. Clin. Oncol.* 32, 1480–1501. doi:10.1200/JCO.2013.53.5948
- Lam, W.W.T., Law, W.-L., Poon, J.T.C., Fong, D., Girgis, A., Fielding, R., 2016. A longitudinal study of supportive care needs among Chinese patients awaiting colorectal cancer surgery. *Psychooncology.* 25, 496–505. doi:10.1002/pon.3946
- Landers, M., McCarthy, G., Livingstone, V., Savage, E., 2014. Patients' bowel symptom experiences and self-care strategies following sphincter-saving surgery for rectal cancer. *J. Clin. Nurs.* 23, 2343–2354. doi:10.1111/jocn.12516
- Li, W.W., Lam, W.W., Au, a H., Ye, M., Law, W.L., Poon, J., Kwong, a, Suen, D., Tsang, J., Girgis, a, Fielding, R., 2012. Interpreting differences in patterns of supportive care needs between patients with breast cancer and patients with colorectal cancer. *Psychooncology.* 798, 792–798. doi:10.1002/pon.3068
- Lithner, M., Johansson, J., Andersson, E., Jakobsson, U., Palmquist, I., Klefsgard, R., 2012. Perceived information after surgery for colorectal cancer - an explorative study. *Color. Dis.* 14, 1340–1350. doi:10.1111/j.1463-1318.2012.02982.x
- Lithner, M., Klefsgard, R., Johansson, J., Andersson, E., 2015. The significance of information after discharge for colorectal cancer surgery-a qualitative study. *BMC Nurs.* 14, 36. doi:10.1186/s12912-015-0086-6
- Lowery, A., 2014. Insomnia Screening and Treatment in Cancer Care: Current Practices, Barriers and Future Directions. *JSM Clin. Oncol. Res.* 2, 1026–1031.
- Macvean, M.L., White, V.M., Pratt, S., Grogan, S., Sanson-Fisher, R., 2007. Reducing the unmet needs of patients with colorectal cancer: a feasibility study of The Pathfinder Volunteer Program. *Support. Care Cancer* 15, 293–9. doi:10.1007/s00520-006-0128-4
- Maguire, R., Kotronoulas, G., Simpson, M., Paterson, C., 2015. A systematic review of the supportive care needs

- of women living with and beyond cervical cancer. *Gynecol. Oncol.* 136, 478–490. doi:10.1016/j.ygyno.2014.10.030
- Maguire, R., Papadopoulou, C., Kotronoulas, G., Simpson, M.F., McPhelim, J., Irvine, L., 2013. A systematic review of supportive care needs of people living with lung cancer. *Eur. J. Oncol. Nurs.* 17, 449–464. doi:10.1016/j.ejon.2012.10.013
- McCaughan, E., Prue, G., Parahoo, K., McIlfratrick, S., McKenna, H., 2012. Exploring and comparing the experience and coping behaviour of men and women with colorectal cancer after chemotherapy treatment: A qualitative longitudinal study. *Psychooncology*. 21, 64–71. doi:10.1002/pon.1871
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ* 339, b2535. doi:10.1136/bmj.b2535
- Morrison, V., Henderson, B.J., Zinovieff, F., Davies, G., Cartmell, R., Hall, A., Gollins, S., 2012. Common, important, and unmet needs of cancer outpatients. *Eur. J. Oncol. Nurs.* 16, 115–123. doi:10.1016/j.ejon.2011.04.004
- Morse, M. a, 2006. Supportive care in the management of colon cancer. *Support Cancer Ther* 3, 158–170.
- Nikoletti, S., Young, J., Levitt, M., King, M., Chidlow, C., Hollingsworth, S., 2008. Bowel problems, self-care practices, and information needs of colorectal cancer survivors at 6 to 24 months after sphincter-saving surgery. *Cancer Nurs.* 31, 389–98. doi:10.1097/01.NCC.0000305759.04357.1b
- Northouse, L.L., Schafer, J.A., Tipton, J., Metivier, L., 1999. The concerns of patients and spouses after the diagnosis of colon cancer: a qualitative analysis. *J. Wound. Ostomy Continence Nurs.* 26, 8–17. doi:10.1016/S1071-5754(99)90005-0
- Ohlsson-Nevo, E., Andershed, B., Nilsson, U., 2016. Psycho-educational intervention on mood in patients suffering from colorectal and anal cancer: A randomized controlled trial. *Nord. J. Nurs. Res.* 205715851667979. doi:10.1177/2057158516679790
- Papagrigoriadis, S., Heyman, B., 2003. Patients' views on follow up of colorectal cancer: implications for risk communication and decision making. *Postgrad. Med. J.* 79, 403–407. doi:10.1136/pmj.79.933.403
- Pullar, J.M., Chisholm, A., Jackson, C., 2012. Dietary information for colorectal cancer survivors: An unmet need. *N. Z. Med. J.* 125, 27–37.
- Raingeruber, B., Bonnie, 2011. The effectiveness of psychosocial interventions with cancer patients: an integrative review of the literature (2006-2011). *ISRN Nurs.* 2011, 638218. doi:10.5402/2011/638218
- Ran, L., Jiang, X., Qian, E., Kong, H., Wang, X., Liu, Q., 2016. Quality of life, self-care knowledge access, and self-care needs in patients with colon stomas one month post-surgery in a Chinese Tumor Hospital. *Int. J. Nurs. Sci.* 3, 252–258. doi:10.1016/j.ijnss.2016.07.004
- Ream, E., Quennell, A., Fincham, L., Faithfull, S., Khoo, V., Wilson-Barnett, J., Richardson, A., 2008. Supportive care needs of men living with prostate cancer in England: a survey. *Br J Cancer* 98, 1903–1909. doi:10.1038/sj.bjc.6604406
- Rittenberg, C.N., Johnson, J.L., Kuncio, G.M., 2010. An oral history of MASCC, its origin and development from MASCC's beginnings to 2009. *Support Care Cancer* 18, 775–784. doi:10.1007/s00520-010-0830-0
- Rozmovits, L., Rose, P., Ziebland, S., 2004. In the absence of evidence, who chooses? A qualitative study of patients' needs after treatment for colorectal cancer. *J. Health Serv. Res. Policy* 9, 159–164. doi:10.1258/1355819041403231
- Russell, L., Gough, K., Drosowsky, A., Schofield, P., Aranda, S., Butow, P.N., Westwood, J.A., Krishnasamy, M., Young, J.M., Phipps-Nelson, J., King, D., Jefford, M., 2015. Psychological distress, quality of life, symptoms and unmet needs of colorectal cancer survivors near the end of treatment. *J. Cancer Surviv.* 9, 462–470. doi:10.1007/s11764-014-0422-y
- Sahay, T.B., Gray, R.E., 2000. A qualitative study of patient perspectives on colorectal cancer 8, 38–44.
- Salamonsen, A., Kiil, M.A., Kristoffersen, A., Stub, T., Berntsen, G., 2016. "My cancer is not my deepest concern": life course disruption influencing patient pathways and health care needs among persons living with colorectal cancer. *Patient Prefer. Adherence* Volume 10, 1591–1600. doi:10.2147/PPA.S108422
- Sales, P.M.G., Carvalho, A.F., McIntyre, R.S., Pavlidis, N., Hyphantis, T.N., 2014. Psychosocial predictors of health outcomes in colorectal cancer: A comprehensive review. *Cancer Treat. Rev.* 40, 800–809. doi:10.1016/j.ctrv.2014.03.001
- Salkeld, G., Solomon, M., Short, L., Butow, P.N., 2004. A matter of trust - patient's views on decision-making in colorectal cancer. *Health Expect.* 7, 104–114. doi:10.1111/j.1369-7625.2004.00257.x
- Salz, T., Baxi, S.S., Blinder, V.S., Elkin, E.B., Kemeny, M.M., McCabe, M.S., Moskowitz, C.S., Onstad, E.E., Saltz, L.B., Temple, L.K.F., Frcs, C., Oeffinger, K.C., 2014. Colorectal Cancer Survivors' Needs and Preferences for Survivorship Information. *J. Oncol. Pract.* e277-82. doi:10.1200/JOP.2013.001312
- Sanoff, H.K., Goldberg, R.M., Pignone, M.P., 2010. Assessing the quality of initial consultations regarding adjuvant colon cancer therapy. *Clin. Colorectal Cancer* 9, 113–8. doi:10.3816/CCC.2010.n.016
- Santin, O., Murray, L., Prue, G., Gavin, A., Gormley, G., Donnelly, M., 2015. Self-reported psychosocial needs and health-related quality of life of colorectal cancer survivors. *Eur. J. Oncol. Nurs.* 19, 336–342.

- doi:10.1016/j.ejon.2015.01.009
- Schünemann, H., Brožek, J., Guyatt, G., Oxman, A., 2013. GRADE handbook for grading quality of evidence and strength of recommendations. GRADE Work. Gr.
- Shun, S.-C., Yeh, K.-H., Liang, J.-T., Huang, J., Chen, S.-C., Lin, B.-R., Lee, P.-H., Lai, Y.-H., 2014. Unmet supportive care needs of patients with colorectal cancer: significant differences by type D personality. *Oncol. Nurs. Forum* 41, E3-11. doi:10.1188/14.ONF.E3-E11
- Simard, S., Thewes, B., Humphris, G., Dixon, M., Hayden, C., Mireskandari, S., Ozakinci, G., 2013. Fear of cancer recurrence in adult cancer survivors: A systematic review of quantitative studies. *J. Cancer Surviv.* doi:10.1007/s11764-013-0272-z
- Sjövall, K., Gunnars, B., Olsson, H., Thomé, B., 2011. Experiences of living with advanced colorectal cancer from two perspectives - Inside and outside. *Eur. J. Oncol. Nurs.* 15, 390-397. doi:10.1016/j.ejon.2010.11.004
- Taylor, C., Cummings, R., McGilly, C., 2012. Holistic needs assessment following colorectal cancer treatment. *Gastrointest. Nurs.* 10, 42-49.
- Traa, M.J., De Vries, J., Roukema, J.A., Rutten, H.J.T., Den Ouden, B.L., 2014. The sexual health care needs after colorectal cancer: The view of patients, partners, and health care professionals. *Support. Care Cancer* 22, 763-772. doi:10.1007/s00520-013-2032-z
- van der Sijp, M.P.L., Bastiaannet, E., Mesker, W.E., van der Geest, L.G.M., Breugom, A.J., Steup, W.H., Marinelli, A.W.K.S., Tseng, L.N.L., Tollenaar, R.A.E.M., van de Velde, C.J.H., Dekker, J.W.T., 2016. Differences between colon and rectal cancer in complications, short-term survival and recurrences. *Int. J. Colorectal Dis.* 31, 1683-1691. doi:10.1007/s00384-016-2633-3
- Vodermaier, A., Linden, W., MacKenzie, R., Greig, D., Marshall, C., 2011. Disease stage predicts post-diagnosis anxiety and depression only in some types of cancer. *Br. J. Cancer* 105, 1814-1817. doi:10.1038/bjc.2011.503
- Walling, A.M., Keating, N.L., Kahn, K.L., Dy, S., Mack, J.W., Malin, J., Arora, N.K., Adams, J.L., Antonio, A.L., Tisnado, D., 2016. Lower Patient Ratings of Physician Communication Are Associated With Unmet Need for Symptom Management in Patients With Lung and Colorectal Cancer. *J Oncol Pr.* 12, e654-69. doi:10.1200/jop.2015.005538
- Wiljer, D., Walton, T., Gilbert, J., Boucher, A., Ellis, P.M., Schiff, S., Sellick, S.M., Simunovic, M., Kennedy, E., Urowitz, S., 2013. Understanding the needs of colorectal cancer patients during the pre-diagnosis phase. *J. Cancer Educ.* 28, 402-407. doi:10.1007/s13187-013-0465-1
- Worster, B., Holmes, S., 2008. The preoperative experience of patients undergoing surgery for colorectal cancer: A phenomenological study. *Eur. J. Oncol. Nurs.* 12, 418-424. doi:10.1016/j.ejon.2008.05.007
- Young, J., Harrison, J., Solomon, M., Butow, P., Dennis, R., Robson, D., Auld, S., 2010. Development and feasibility assessment of telephone-delivered supportive care to improve outcomes for patients with colorectal cancer: pilot study of the CONNECT intervention. *Support. Care Cancer* 18, 461-70. doi:10.1007/s00520-009-0689-0
- Zullig, L.L., Jackson, G.L., Provenzale, D., Griffin, J.M., Phelan, S., Van Ryn, M., 2012. Transportation - A vehicle or roadblock to cancer care for VA patients with colorectal cancer? *Clin. Colorectal Cancer* 11, 60-65. doi:10.1016/j.clcc.2011.05.001

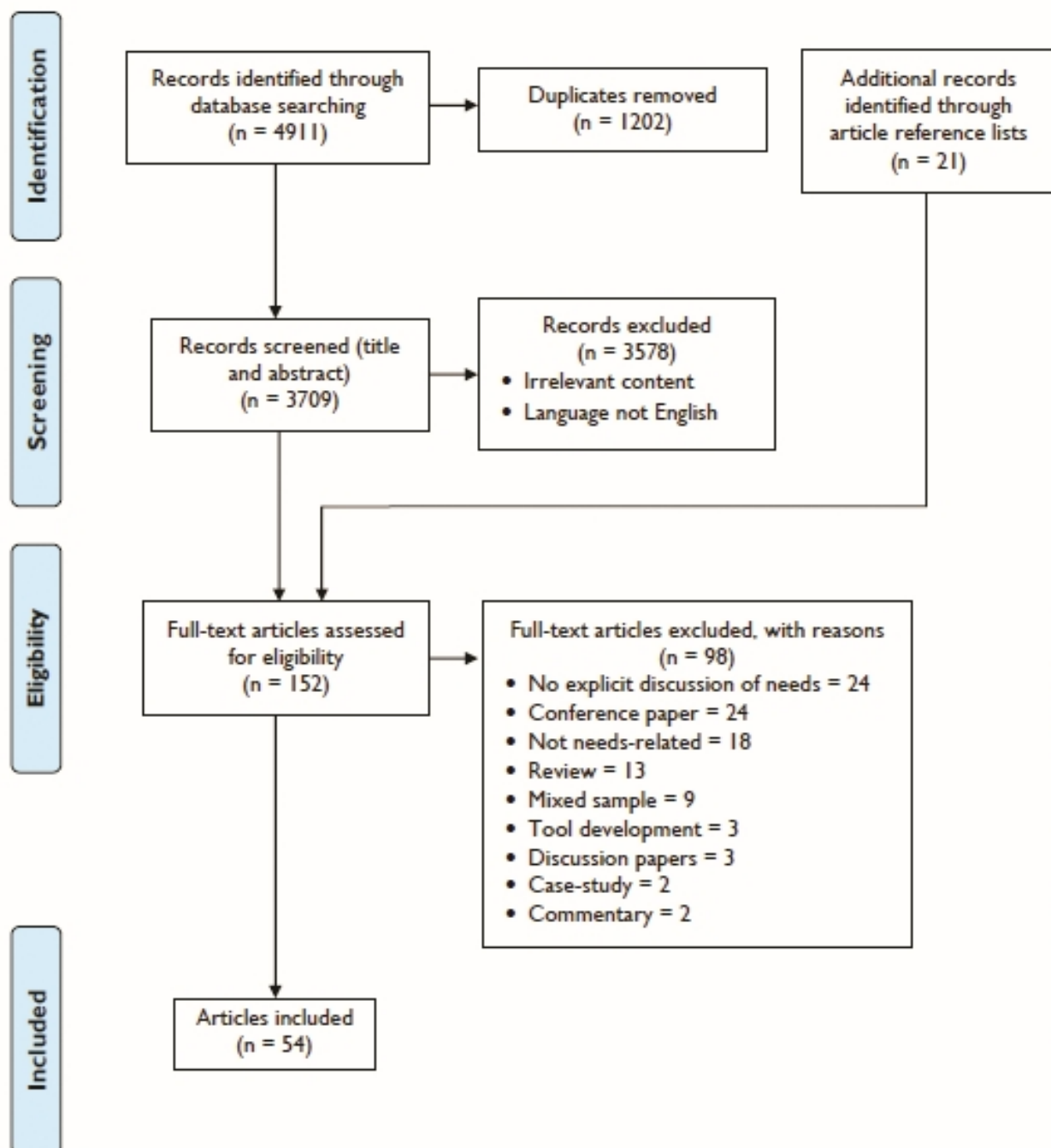


Table 1. Top twenty (top ten in shaded section) most prominent individual needs for people with cancer of the colon and/or rectum based on frequency of reporting within and across the reviewed studies

| Ranking | Domain | Need for... | Aggregate SQS: Median; range |
|---------|---|---|----------------------------------|
| 1 | Psychosocial/emotional | Emotional support and reassurance (16-33%) (Hansen et al., 2013; Harrison et al., 2011; Holm et al., 2012; Jorgensen et al., 2012; Morrison et al., 2012; Salamonsen et al., 2016; Wiljer et al., 2013) when trying to deal with fear of the cancer returning or spreading (20-56%) (Anderson et al., 2013; Boudioni et al., 2001; Browne et al., 2011; Ho et al., 2016; Jefford et al., 2011; Klemm et al., 2000; Macvean et al., 2007; Northouse et al., 1999; Russell et al., 2015; Santin et al., 2015; Shun et al., 2014; Taylor et al., 2012) | 85%; 70%-90% 76%; 70%-95% |
| 2 | Information/education | More information about diet/nutrition (46-98%) (Anderson et al., 2013; Beaver et al., 2010; Beckjord et al., 2008; Boudioni et al., 2001; Cha et al., 2012; Dunn et al., 2006; Harrison et al., 2011; Knowles et al., 1999; Lithner et al., 2015; Nikolett et al., 2008; Pullar et al., 2012; Rozmovits et al., 2004; Sahay and Gray, 2000; Salz et al., 2014; Taylor et al., 2012) in the form of a pamphlet (90%) or by a hospital dietician (53%) (Pullar et al., 2012) | 73%; 44%-95% |
| 3 | Information/education | More information about the long-term self-management of symptoms and complications at home, e.g. persistent fatigue and bowel symptoms (7-89%) (Baravelli et al., 2009; Beaver et al., 2010; Beckjord et al., 2008; Dunn et al., 2006; Galloway and Graydon, 1996; Husson, 2013; Knowles et al., 1999; Lam et al., 2016; Li et al., 2012; Lithner et al., 2012; Nikolett et al., 2008; Northouse et al., 1999; Sahay and Gray, 2000; Salz et al., 2014; Shun et al., 2014) | 82%; 64%-95% |
| 4 | Health system/patient-clinician communication | Information that is clear/straight-forward, up-to-date, honest, unhurried, and given in a sensitive way (14-99%), especially if no curative treatment is available (29-38%) (Andersson et al., 2010; Bain and Campbell, 2000; Bain et al., 2002; Ho et al., 2016; Jefford et al., 2011; Lithner et al., 2015, 2012; Morrison et al., 2012; Russell et al., 2015; Salkeld et al., 2004; Salz et al., 2014; Santin et al., 2015; Sjövall et al., 2011) | 80%; 61%-95% |
| 5 | Health system/patient-clinician communication | Written information/publications (21-75%) (Anderson et al., 2013; Boudioni et al., 2001; Ho et al., 2016; Lam et al., 2016; Li et al., 2012; Lithner et al., 2015, 2012; Salz et al., 2014), especially about treatment options/processes (72-78%) (Baravelli et al., 2009; Beaver et al., 2010; Salkeld et al., 2004) | 85%; 62%-95% 83%; 80%-86% |
| 6 | Information/ education | More information about cancer staging and prognosis (59-60%) (Beaver et al., 1999; Boudioni et al., 2001; Husson, 2013; Klemm et al., 2000; Knowles et al., 1999; Li et al., 2012; Lithner et al., 2012; Salz et al., 2014; Sanoff et al., 2010; Sjövall et al., 2011) | 81%; 64%-95% |
| 7 | Physical/cognitive | Help with fatigue/lack of energy (23-32%) (Anderson et al., 2013; Browne et al., 2011; Northouse et al., 1999; Taylor et al., 2012; Walling et al., 2016) post-op (12-27%) (Carlsson et al., 2010; Harrison et al., 2011; Macvean et al., 2007; Santin et al., 2015) | 70%; 44%-90% 67%; 46%-73% |
| 8 | Information/education | More information about the risk of recurrence (46-63%) (Beckjord et al., 2008; Boudioni et al., 2001; Papagrigoriadis and Heyman, 2003; Salz et al., 2014; Sanoff et al., 2010) and/or symptoms of disease recurrence (89%) (Beckjord et al., 2008; Knowles et al., 1999; Lithner et al., 2015) | 81%; 64%-95% 85%; 65%-95% |
| 9 | Information/education | More information about the short-term and long-term effects of treatment on quality of life (40-78%) (Boudioni et al., 2001; Galloway and Graydon, 1996; Harrison et al., 2011; Kidd, 2014; Knowles et al., 1999; Morrison et al., 2012; Rozmovits et al., 2004; Sanoff et al., 2010) | 83%; 73%-90% |
| 10 | Health system/patient-clinician communication | On-going communication/contact with and support from a trustworthy clinician (16-56%) (Jefford et al., 2011; Lam et al., 2016; Li et al., 2012; Lithner et al., 2015, 2012; Rozmovits et al., 2004; Santin et al., 2015; Shun et al., 2014) | 86%; 61%-95% |
| 11 | Physical/cognitive | Help with pain (abdominal) (23-28%) (Anderson et al., 2013; Browne et al., 2011; Di Fabio et al., 2008; Northouse et al., 1999; Taylor et al., 2012; Walling et al., 2016) post-op associated with adhesions/infected wounds/non-healing wounds (Browne et al., 2011; Carlsson et al., 2010; Harrison et al., 2011) | 70%; 44%-90% 73%; 73%-90% |
| 12 | Information/education | More information about the exact diagnosis and what it means (52-80%) (Andersson et al., 2010; Baravelli et al., 2009; Boudioni et al., 2001; Harrison et al., 2011; Lithner et al., 2015; Ran et al., 2016; Sanoff et al., 2010) | 78%; 50%-90% |
| 13 | Information/education | More information about test results and procedures (21-77%) (Beckjord et al., 2008; Knowles et al., 1999; Lam et al., 2016; Li et al., 2012; Lithner et al., 2012; Northouse et al., 1999; Shun et al., 2014) | 91%; 70%-95% |
| 14 | Health system/patient-clinician communication | Healthcare professional who treats the patient like a person, not just another case (14-32%) (Lam et al., 2016; Li et al., 2012), listens to what the patient has to say (94%) (Salkeld et al., 2004), is open and sincere, | 93%; 91%-95% |




| | | | |
|---|---|--|---|
| | | and acknowledges and shows sensitivity to patients' feelings/emotions (16%) (Ho et al., 2016; Li et al., 2012; Morrison et al., 2012) and/or to family/friends' feelings (Morrison et al., 2012) | 85%; 80%-91%  |
| 15 | Family-related | Help with the worries/concerns of one's family (24-38%) (Hansen et al., 2013; Holm et al., 2012; Macvean et al., 2007; Shun et al., 2014), especially children (55%) (Klemm et al., 2000; Sjövall et al., 2011; Worster and Holmes, 2008) | 86%; 46%-90%  80%; 75%-85% |
| 16 | Health system/patient-clinician communication | Better coordination/communication among healthcare professionals (primary and secondary care) (15-68%) (Bain and Campbell, 2000; Bain et al., 2002; Jefford et al., 2011; Northouse et al., 1999; Russell et al., 2015; Salamonsen et al., 2016; Santin et al., 2015) | 72%; 61%-90% |
| 17 | Interpersonal/ intimacy | Help to adjust to changes in/problems with sexuality especially if partnered (12-48%) (Andersson et al., 2010; Hansen et al., 2013; Holm et al., 2012; Jefford et al., 2011; Santin et al., 2015; Taylor et al., 2012; Traa et al., 2014) | 72%; 44%-90% |
| 18 | Information/education | More information about what to expect following discharge (Galloway and Graydon, 1996; Harrison et al., 2011; Lithner et al., 2012; Salz et al., 2014) or following chemotherapy (Knowles et al., 1999), especially people with no stoma (Beaver et al., 2010; Northouse et al., 1999) | 74%; 64%-95%  75%; 70%-80% |
| 19 | Psychosocial/emotional | Support when dealing with uncertainty about the future (33-35%) (Browne et al., 2011; Carlsson et al., 2010; Klemm et al., 2000; Macvean et al., 2007; Northouse et al., 1999; Shun et al., 2014) | 77%; 46%-90% |
| 20 | Information/education | More information about specific treatment modalities (mainly, chemotherapy) and side-effects whilst on treatment (13-48%) (Boudioni et al., 2001; Harrison et al., 2011; Kidd, 2014; Knowles et al., 1999; Lam et al., 2016; Morrison et al., 2012) | 85%; 73%-95% |
| SQS – Summary Quality Score; Aggregate SQS to be interpreted as follows: SQS>95% - High quality evidence; SQS=90%-95% - Very good quality evidence; SQS=80%-89% - Good quality evidence; SQS=65%-79% - Moderate quality evidence; SQS=40%-64% - Low quality evidence. | | | |

Table 2. Covariates of supportive care needs in people with cancer of the colon and/or rectum across the reviewed studies

| Covariate | Covariate category | Reported significant associations (p<0.05) |
|--|--|--|
| Demographic (Median SQS=83%; range=61%-95%) | Women (Median SQS=87%; range=73%-95%) | <ul style="list-style-type: none"> • Greater need for support post-chemotherapy (McCaughan et al., 2012) • More likely to opt for a shared decision role (Salkeld et al., 2004) • Higher post-operative concerns regarding 'producing unpleasant odours', 'feeling dirty or smelly', 'pain or suffering', 'having an ostomy pouch', and 'feeling alone' (Carlsson et al., 2010) • Less likely to report receipt of information (Lithner et al., 2012) • More information needs about complementary therapies (Boudioni et al., 2001) • Fewer concerns about prognosis (Boudioni et al., 2001) |
| | Younger patients (Median SQS=82%; range=61%-86%) | <ul style="list-style-type: none"> • More likely to opt for a shared decision role (Salkeld et al., 2004) • Higher concerns about physical symptoms, social relationships, family functioning, self-image and treatment issues (Klemm et al., 2000) • More likely to express an unmet need (Harrison et al., 2011; Santin et al., 2015) • Higher levels of unmet need in all domains except patient care/support at 1 month after hospital discharge, and except patient care/support and health system/information at 3 months post-hospital discharge (Jorgensen et al., 2012) • More likely to report 'satisfied' needs at 1 month after hospital discharge (Jorgensen et al., 2012) |
| | Higher education attainment (Median SQS=89%; range=83%-95%) | <ul style="list-style-type: none"> • Less likely to feel the need to let the family have a say about their treatment (Salkeld et al., 2004) • More likely to have moderate and stable health system and information needs from pre-surgery to 12 months post-surgery (Lam et al., 2016) |
| | Employed | <ul style="list-style-type: none"> • Greater need for emotional support (especially men) (Boudioni et al., 2001) |
| | Have no family support | <ul style="list-style-type: none"> • More likely to experience transportation problems (Zullig et al., 2012) |
| Clinical (Median SQS=85%; range=67%-95%) | Overweight/obese | <ul style="list-style-type: none"> • More interested in receiving additional dietary advice (Pullar et al., 2012) |
| | Have uncontrolled pain | <ul style="list-style-type: none"> • More likely to experience transportation problems (Zullig et al., 2012) |
| | Received treatment within previous 2 m | <ul style="list-style-type: none"> • More concerns about symptoms, monitoring symptoms, treatment issues, family functioning and social relationships (Klemm et al., 2000) |
| | Have rectal cancer | <ul style="list-style-type: none"> • More likely to require more than one contact with the nurse to satisfy a need (Harrison et al., 2011) • More likely to report a physical need (Harrison et al., 2011) |
| | Have stoma | <ul style="list-style-type: none"> • More likely to have moderate-to-high psychological/emotional needs that decline from pre-surgery to 12 months post-surgery (Lam et al., 2016) • More likely to have high and stable or moderate but declining physical/daily living needs from pre-surgery to 12 months post-surgery (Lam et al., 2016) |
| | Poorer pre-operative health status | <ul style="list-style-type: none"> • Less likely to report receipt of information (Lithner et al., 2012) |
| | More bowel symptoms | <ul style="list-style-type: none"> • More likely to express a need to plan social events ahead (Landers et al., 2014) |
| | Shorter symptom duration | <ul style="list-style-type: none"> • More likely to express a need to plan social events ahead (Landers et al., 2014) |
| Psycho-social (Median SQS=86%; range=75%-95%) | Late disease stage | <ul style="list-style-type: none"> • Greater need for help with any symptom, pain, fatigue, nausea/vomiting and diarrhoea (Walling et al., 2016) |
| | Perceive illness uncontrolled/terminal | <ul style="list-style-type: none"> • More concerns about symptoms, monitoring symptoms, treatment issues, family functioning and social relationships (Klemm et al., 2000) |
| | Doubt that treatment will control the disease | <ul style="list-style-type: none"> • More likely to express a need to plan social events ahead (Landers et al., 2014) |
| | Have higher uncertainty | <ul style="list-style-type: none"> • More information needs at discharge (Galloway and Graydon, 1996) |
| | Pre-surgical physical symptom distress | <ul style="list-style-type: none"> • More likely to have moderate physical/daily living needs that decline from pre-surgery to 12 months post-surgery (Lam et al., 2016) |
| | Pre-surgical positive cancer-related rumination | <ul style="list-style-type: none"> • More likely to have moderate and stable health system and information needs from pre-surgery to 12 months post-surgery (Lam et al., 2016) |
| | Pre-surgical negative | <ul style="list-style-type: none"> • More likely to have patient care and support needs that increase 8-12 |

| Covariate | Covariate category | Reported significant associations (p<0.05) |
|--|---------------------------|--|
| | cancer-related rumination | months post-surgery (Lam et al., 2016) |
| | Pre-surgical depression | <ul style="list-style-type: none"> • More likely to have high patient care and support needs that decline from pre-surgery to 12 months post-surgery (Lam et al., 2016) |
| | Type D personality | <ul style="list-style-type: none"> • Higher demands in overall supportive care needs and in most domains, except for sexuality needs (Shun et al., 2014) |
| Notes: SQS – Summary quality score. Median SQS are presented per covariate category with at least two studies. Higher SQS indicate better methodological quality. Aggregate SQS to be interpreted as follows: SQS>95% - High quality evidence; SQS=90%-95% - Very good quality evidence; SQS=80%-89% - Good quality evidence; SQS=65%-79% - Moderate quality evidence; SQS=40%-64% - Low quality evidence. For methodological details on individual studies, see Table S3. | | |

Abstract

Purpose: Gaining a clear understanding of the health needs and concerns of people with cancer of the colon and/or rectum can help identify ways to offer a comprehensive care package. Our aim was to systematically assess the relevant literature and synthesise current available evidence.

Methods: A systematic review was conducted according to the PRISMA Statement guidelines. Five electronic databases were searched to identify studies employing qualitative and/or quantitative methods. Pre-specified selection criteria were applied to all retrieved records. Findings were integrated in a narrative synthesis.

Results: Of 3709 references initially retrieved, 54 unique studies were retained. A total of 136 individual needs were identified and classified into eight domains. Just over half of the needs (70; 51%) **concerned information/education or health system/patient-clinician communication issues**. Emotional support and reassurance when trying to deal with **fear of cancer recurrence** featured as the most prominent need regardless of clinical stage or phase of treatment. Information about diet/nutrition and about long-term self-management of symptoms and complications at home; tackling issues relating to the quality and mode of delivery of health-related information; help with controlling fatigue; and on-going contact with a trustworthy health professional also featured as salient needs. **Available research evidence is of moderate-to-good quality.**

Conclusions: Investing time to sensitively inquire about the supportive care needs of this patient population is key, whilst evaluating and re-shaping clinical interactions based on patients' priorities is equally essential. The diverse needs identified require a multi-professional and multi-agency approach to ensure unmet needs are addressed or measures offered.

Keywords: Supportive care; Supportive care needs; Colorectal cancer; Colon cancer; Rectum cancer; Unmet needs; Patient-centred care; Patient-reported outcomes; Systematic review

Highlights

- Based on moderate-to-good quality research evidence, a total of 136 individual needs were identified and classified into eight domains. Just over half of the needs (70; 51%) concerned information/education (36; 26.5%) or health system/patient-clinician communication issues (34; 25%).
- Emotional support and reassurance when trying to deal with fear of the cancer returning or spreading featured as the most prominent need regardless of clinical stage or phase of treatment.
- Additional salient needs included information about diet/nutrition and about long-term self-management of symptoms and complications at home; tackling issues relating to the quality and mode of delivery of health-related information; help with controlling fatigue; and on-going contact with a trustworthy health professional.
- The diverse needs identified require a multi-professional and multi-agency approach to ensure unmet needs are addressed or measures offered.

SUPPLEMENTARY MATERIAL

Table S1. Electronic databases searched and search terms used

| Electronic databases | Search terms ^a |
|---|---|
| Ovid Medline® MEDLINE (1946 – October 2016) EMBASE (1974 – October 2016) CINAHL (Inception – October 2016) PsychINFO (Inception – October 2016) | <ol style="list-style-type: none"> Care adj1 need\$.mp. or patient\$ adj1 need\$.mp. or need\$ adj1 assess\$.mp. or support\$ adj1 care adj1 need\$.mp. or unmet adj1 need\$.mp. or healthcare need\$.mp. Colorectal adj1 cancer.mp. or exp colorectal neoplasms/ 1 and 2 Limit 3 to English language Exclude duplicates |
| PubMed (Inception – October 2016) | <ol style="list-style-type: none"> TX patient need* or TX needs assessment* or TX care need* or TX supportive care need* or TX unmet need* or TX healthcare need* or TX health care need* or TX health concern* or TX need for support (MESHterms) carcinoma, colorectal 1 and 2 Limit 3 to English language |
| Note: exp / – MeSH | |

Table S2. Individual supportive care needs of people with cancer classified into need domains and ranked for prominence within each need domain

| Need domain | Operational definition | Evidence: Need for/to... | Aggregate SQS: Median; range |
|-------------------------------|--|--|------------------------------|
| a. Physical/ Cognitive | Need for help with symptom management of cancer-related problems and treatment-related toxicity, and cognitive dysfunction | Help with symptom control (6-62%) (Hansen et al., 2013; Holm et al., 2012; Jorgensen et al., 2012; Lam et al., 2016; Northouse et al., 1999; Russell et al., 2015; Walling et al., 2016) especially: | 86%; 70%-95% |
| | | 1. <u>Fatigue/lack of energy</u> (23-32%) (Anderson et al., 2013; Browne et al., 2011; Northouse et al., 1999; Taylor et al., 2012; Walling et al., 2016) <u>post-op</u> (12-27%) (Carlsson et al., 2010; Harrison et al., 2011; Macvean et al., 2007; Santin et al., 2015) | 70%; 44%-90% 67%; 46%-73% |
| | | 2. <u>Pain (abdominal)</u> (23-28%) (Anderson et al., 2013; Browne et al., 2011; Di Fabio et al., 2008; Northouse et al., 1999; Taylor et al., 2012; Walling et al., 2016) <u>post-op associated with adhesions/infected wounds/non-healing wounds</u> (Browne et al., 2011; Carlsson et al., 2010; Harrison et al., 2011) | 70%; 44%-90% 73%; 73%-90% |
| | | 3. <u>Defecation problems (gas/wind, diarrhoea, constipation)</u> (21-26%) (Browne et al., 2011; Di Fabio et al., 2008; Harrison et al., 2011; Taylor et al., 2012; Walling et al., 2016) | 73%; 44%-90% |
| | | 4. <u>Digestive problems/dysfunction</u> (18-31%) (nausea, indigestion; appetite; taste) (Browne et al., 2011; Di Fabio et al., 2008; Harrison et al., 2011; Ho et al., 2016; Walling et al., 2016) | 77%; 70%-90% |
| | | 5. <u>Sleep loss</u> (Anderson et al., 2013; Northouse et al., 1999) <u>post-op</u> (29%) (Browne et al., 2011; Macvean et al., 2007) | 66%; 62%-70% 68%; 46%-90% |
| | | 6. Cognitive alterations (Ho et al., 2016; Taylor et al., 2012) | 62%; 44%-80% |
| | | 7. Weight changes (loss/gain) (Anderson et al., 2013) | — |
| | | 8. Infection (Harrison et al., 2011) | — |
| | | 9. Peripheral neuropathy (Ho et al., 2016) | — |
| b. Psychosocial/ emotional | Need for help with psychological/emotional symptoms such as depressive mood, anxiety, fear/worry, despair | 1. <u>Emotional support and reassurance</u> (16-33%) (Hansen et al., 2013; Harrison et al., 2011; Holm et al., 2012; Jorgensen et al., 2012; Morrison et al., 2012; Salamonsen et al., 2016; Wiljer et al., 2013) <u>when trying to deal with fear of the cancer returning or spreading</u> (20-56%) (Anderson et al., 2013; Boudioni et al., 2001; Browne et al., 2011; Ho et al., 2016; Jefford et al., 2011; Klemm et al., 2000; Macvean et al., 2007; Northouse et al., 1999; Russell et al., 2015; Santin et al., 2015; Shun et al., 2014; Taylor et al., 2012) | 85%; 70%-90% 76%; 70%-95% |
| | | 2. <u>Support when dealing with uncertainty about the future</u> (33-35%) (Browne et al., 2011; Carlsson et al., 2010; Klemm et al., 2000; Macvean et al., 2007; Northouse et al., 1999; Shun et al., 2014) | 77%; 46%-90% |

| Need domain | Operational definition | Evidence: Need for/to... | Aggregate SQS: Median; range |
|---------------------------|--|---|------------------------------|
| | | 3. <u>Support to come to terms with the diagnosis and deal with feelings of shock and mental isolation</u> (Carlsson et al., 2010; Salamonsen et al., 2016; Worster and Holmes, 2008) | 73%; 73%-85% |
| | | 4. <u>Psychological support</u> (Di Fabio et al., 2008) especially in relation to feelings of abandonment after treatment is over (Ho et al., 2016; McCaughan et al., 2012) | 77%; 75%-80% |
| | | 5. <u>Support with concerns about being a burden or dependent on others (29%)</u> (Carlsson et al., 2010; Macvean et al., 2007) | 60%; 46%-73% |
| | | 6. <u>Support with concerns about not being able to enjoy their family in the future</u> (Northouse et al., 1999; Sjövall et al., 2011) | 73%; 70%-75% |
| | | 7. <u>Support with fear of dying early</u> (Carlsson et al., 2010) | — |
| | | 8. <u>Support with fear of loss of bowel control</u> (Carlsson et al., 2010) | — |
| | | 9. <u>Help with anxiety about having any treatment (24%)</u> (Macvean et al., 2007) | — |
| | | 10. <u>Help with depressed mood (15-19%)</u> (Walling et al., 2016) | — |
| c. Family-related | Need for help with dysfunctional family relationships, fears/concerns for family future | 1. <u>Help with the worries/concerns of one's family (24-38%)</u> (Hansen et al., 2013; Holm et al., 2012; Macvean et al., 2007; Shun et al., 2014), especially children (55%) (Klemm et al., 2000; Sjövall et al., 2011; Worster and Holmes, 2008) | 86%; 46%-90% 80%; 75%-85% |
| | | 2. <u>Support with concerns about the family's future</u> (Klemm et al., 2000; Sjövall et al., 2011; Taylor et al., 2012) | 75%; 44%-80% |
| | | 3. <u>Help with the information needs of family (16%)</u> (Jefford et al., 2011; Santin et al., 2015) | 67%; 61%-72% |
| | | 4. <u>Help with compromised emotional closeness with family</u> (Morrison et al., 2012) | — |
| d. Social/societal | Need for help with experience of social isolation, inefficient social support, diminished socialisation | 1. <u>Access to peer support groups for colorectal cancer survivors (63%)</u> (Anderson et al., 2013; Jefford et al., 2011; McCaughan et al., 2012; Salkeld et al., 2004) | 74%; 62%-83% |
| | | 2. <u>Help with embarrassment/loss of dignity/pride due to stoma issues/uncontrolled bowel movements in social situations (31-36%)</u> (Beaver et al., 2010; Nikoletti et al., 2008) | 80%; 80%-80% |
| | | 3. <u>Know the proximity/location of a toilet at all times (72%)</u> (Landers et al., 2014) | — |
| | | 4. <u>Plan social events ahead (35%)</u> (Landers et al., 2014) | — |
| | | 5. <u>Access support groups to help others</u> (McCaughan et al., 2012) | — |
| | | 6. <u>Help to handle the topic of cancer in social/work situations</u> (Jefford et al., 2011) | — |
| | | 7. <u>Talk about colorectal cancer to raise the disease's public profile</u> (Ho et al., 2016) | — |
| | | 8. <u>Participate in advocacy</u> (Ho et al., 2016) | — |
| e. Interpersonal/intimacy | Need for help with altered body image or sexuality, sexual health problems, compromised intimacy with partner, loss of fertility | 1. <u>Help to adjust to changes in/problems with sexuality especially if partnered (12-48%)</u> (Andersson et al., 2010; Hansen et al., 2013; Holm et al., 2012; Jefford et al., 2011; Santin et al., 2015; Taylor et al., 2012; Traa et al., 2014) | 72%; 44%-90% |
| | | 2. <u>Help to adjust to altered body image/appearance</u> (Andersson et al., 2010; Beaver et al., 2010; Browne et al., 2011; Dunn et al., 2006; Jefford et al., 2011; Taylor et al., 2012) | 76%; 44%-90% |
| | | 3. <u>Help with concerns about sexual impotence/dysfunction</u> (Anderson et al., 2013; Dunn et al., 2006; Traa et al., 2014) | 62%; 60%-70% |
| | | 4. <u>Help with concerns about sexual relationships (18%)</u> (Nikoletti et al., 2008) especially initiating future relationships if unpartnered (Dunn et al., 2006) | 75%; 70%-80% |
| | | 5. <u>Help with changed partner roles and compromised intimacy</u> (Sjövall et al., 2011) | — |
| f. Practical/daily living | Need for help with transportation, living will, out-of-hours accessibility, funeral care, financial strain, experience of restriction in daily living tasks such as housekeeping, exercise | 1. <u>Help in adjusting to the daily restrictions posed by treatment toxicity/altered bowel function/stoma (26%)</u> (Andersson et al., 2010; Browne et al., 2011; Nikoletti et al., 2008; Shun et al., 2014; Sjövall et al., 2011) | 80%; 75%-90% |
| | | 2. <u>Support with transportation/access barriers/issues/difficulties especially for rural patients (19-34%)</u> (Bain and Campbell, 2000; Browne et al., 2011; Zullig et al., 2012), e.g. <u>accessible hospital parking (17%)</u> (Russell et al., 2015; Santin et al., 2015) | 90%; 80%-94% 76%; 61%-90% |
| | | 3. <u>Support with financial issues (23-27%)</u> (Hansen et al., 2013; Holm et al., 2012; Northouse et al., 1999) and/or work-related | 86%; 70%-90% |

| Need domain | Operational definition | Evidence: Need for/to... | Aggregate SQS: Median; range |
|--------------------------|--|---|---------------------------------------|
| | | issues (15-25%) (Hansen et al., 2013; Holm et al., 2012) | 88%; 86%-90% |
| | | 4. <u>Help in recovering/achieving full potential and dealing with the debilitating effects of the illness</u> (Carlsson et al., 2010; Macvean et al., 2007; Northouse et al., 1999) | 70%; 46%-73% |
| | | 5. <u>Support with establishing dietary changes/timing of meals (especially to avoid gas from the stoma or having to change the stoma bag)</u> (Andersson et al., 2010; Beaver et al., 2010; Nikoletti et al., 2008) | 80%; 80%-80% |
| | | 6. Support with performing wound/stoma care (81%) (Northouse et al., 1999; Ran et al., 2016) | 60%; 50%-70% |
| | | 7. Help in maintaining a normal daily life (Harrison et al., 2011; Sjövall et al., 2011) | 74%; 73%-75% |
| | | 8. Support with working around the home (24%) (Macvean et al., 2007) | — |
| | | 9. Help getting life/travel insurance (23%) (Santin et al., 2015) | — |
| | | 10. Support with taking care of personal hygiene (16%) (Nikoletti et al., 2008) | — |
| | | 11. Support with including exercise as part of daily living schedule (13%) (Nikoletti et al., 2008) | — |
| | | 12. Support with reduced mobility (Anderson et al., 2013) | — |
| g. Information/education | Need for help with lack of information, uncertainty about diagnosis/treatment, uncertainty/lack of knowledge about self-care | More information (32-49%) (Husson, 2013; Knowles et al., 1999; Lithner et al., 2012; Northouse et al., 1999; Wiljer et al., 2013) about: | 82%; 70%-95% |
| | | 1. <u>Diet/nutrition (46-98%)</u> (Anderson et al., 2013; Beaver et al., 2010; Beckjord et al., 2008; Boudioni et al., 2001; Cha et al., 2012; Dunn et al., 2006; Harrison et al., 2011; Knowles et al., 1999; Lithner et al., 2015; Nikoletti et al., 2008; Pullar et al., 2012; Rozmovits et al., 2004; Sahay and Gray, 2000; Salz et al., 2014; Taylor et al., 2012) <u>in the form of a pamphlet (90%) or by a hospital dietician (53%)</u> (Pullar et al., 2012) | 73%; 44%-95% — |
| | | 2. <u>Long-term self-management of symptoms and complications at home, e.g. persistent fatigue and bowel symptoms (7-89%)</u> (Baravelli et al., 2009; Beaver et al., 2010; Beckjord et al., 2008; Dunn et al., 2006; Galloway and Graydon, 1996; Husson, 2013; Knowles et al., 1999; Lam et al., 2016; Li et al., 2012; Lithner et al., 2012; Nikoletti et al., 2008; Northouse et al., 1999; Sahay and Gray, 2000; Salz et al., 2014; Shun et al., 2014) | 82%; 64%-95% |
| | | 3. <u>Cancer staging and prognosis (59-60%)</u> (Beaver et al., 1999; Boudioni et al., 2001; Husson, 2013; Klemm et al., 2000; Knowles et al., 1999; Li et al., 2012; Lithner et al., 2012; Salz et al., 2014; Sanoff et al., 2010; Sjövall et al., 2011) | 81%; 64%-95% |
| | | 4. <u>Risk of recurrence (46-63%)</u> (Beckjord et al., 2008; Boudioni et al., 2001; Papagrigoriadis and Heyman, 2003; Salz et al., 2014; Sanoff et al., 2010) <u>and/or symptoms of disease recurrence (89%)</u> (Beckjord et al., 2008; Knowles et al., 1999; Lithner et al., 2015) | 81%; 64%-95% 85%; 65%-95% |
| | | 5. <u>Short-term and long-term effects of treatment on quality of life (40-78%)</u> (Boudioni et al., 2001; Galloway and Graydon, 1996; Harrison et al., 2011; Kidd, 2014; Knowles et al., 1999; Morrison et al., 2012; Rozmovits et al., 2004; Sanoff et al., 2010) | 83%; 73%-90% |
| | | 6. <u>Exact diagnosis and what it means (52-80%)</u> (Andersson et al., 2010; Baravelli et al., 2009; Boudioni et al., 2001; Harrison et al., 2011; Lithner et al., 2015; Ran et al., 2016; Sanoff et al., 2010) | 78%; 50%-90% |
| | | 7. <u>Test results and procedures (21-77%)</u> (Beckjord et al., 2008; Knowles et al., 1999; Lam et al., 2016; Li et al., 2012; Lithner et al., 2012; Northouse et al., 1999; Shun et al., 2014) | 91%; 70%-95% |
| | | 8. <u>What to expect following discharge</u> (Galloway and Graydon, 1996; Harrison et al., 2011; Lithner et al., 2012; Salz et al., 2014) <u>or following chemotherapy</u> (Knowles et al., 1999), <u>especially people with no stoma</u> (Beaver et al., 2010; Northouse et al., 1999) | 74%; 64%-95% — 75%; 70%-80% |
| | | 9. <u>Specific treatment modalities (mainly, chemotherapy) and side-effects whilst on treatment (13-48%)</u> (Boudioni et al., 2001; Harrison et al., 2011; Kidd, 2014; Knowles et al., | 85%; 73%-95% |

| Need domain | Operational definition | Evidence: Need for/to... | Aggregate SQS: Median; range |
|---|--|---|------------------------------|
| | | 1999; Lam et al., 2016; Morrison et al., 2012) | |
| | | 10. Cancer treatment options (22-94%) (Beaver et al., 1999; Li et al., 2012; Northouse et al., 1999; Salkeld et al., 2004; Shun et al., 2014) | 83%; 65%-91% |
| | | 11. Self-managing emotional distress (38-59%) (Baravelli et al., 2009; Beckjord et al., 2008; Husson, 2013; Lithner et al., 2012; Ran et al., 2016) | 86%; 50%-95% |
| | | 12. Things patients can do to help themselves get well/enhance recovery (24-72%) (Beckjord et al., 2008; Lam et al., 2016; Li et al., 2012; Lithner et al., 2015; Shun et al., 2014) | 86%; 65%-95% |
| | | 13. Financial/work-related issues (15-43%) (Baravelli et al., 2009; Beckjord et al., 2008; Jefford et al., 2011; Lithner et al., 2015; Santin et al., 2015) | 72%; 61%-95% |
| | | 14. Post-operative complications and recovery (67%) (Lithner et al., 2015; Morrison et al., 2012; Ran et al., 2016; Sahay and Gray, 2000) | 68%; 50%-85% |
| | | 15. Short-term prevention and management of treatment/illness side-effects (19-52%) (Knowles et al., 1999; Lam et al., 2016; Nikoletti et al., 2008; Shun et al., 2014), mainly diarrhoea, bloating, emptying bowels, pain | 86%; 80%-95% |
| | | 16. Stoma self-care (44%) (Andersson et al., 2010; Northouse et al., 1999; Ran et al., 2016; Sahay and Gray, 2000) | 70%; 50%-84% |
| | | 17. When to increase physical activity/exercise (Anderson et al., 2013; Beckjord et al., 2008; Lithner et al., 2015; Taylor et al., 2012) | 64%; 44%-95% |
| | | 18. Success of treatment in controlling cancer at the end of treatment (8-95%) (Knowles et al., 1999; Lam et al., 2016; Lithner et al., 2015; Shun et al., 2014) | 86%; 65%-95% |
| | | 19. Frequency of follow-up (84%) and scans/tests required (Beckjord et al., 2008; Knowles et al., 1999; Salz et al., 2014) | 85%; 64%-95% |
| | | 20. Available rehabilitation services (Harrison et al., 2011; Husson, 2013; Salz et al., 2014) | 73%; 64%-82% |
| | | 21. When/who to ask for advice for possible short/long-term effects (35-67%) (Baravelli et al., 2009; Knowles et al., 1999) | 86%; 85%-86% |
| | | 22. Correct medication use (57%) (Lithner et al., 2015; Nikoletti et al., 2008) | 73%; 65%-80% |
| | | 23. How to deal with restrictions in daily living (Galloway and Graydon, 1996) and resuming work and social activities (especially in the case of a stoma) (33%) (Knowles et al., 1999) | — — |
| | | 24. Possible consequences of cancer/treatment on sexual function and fertility (32%) (Beckjord et al., 2008; Traa et al., 2014) | 78%; 60%-95% |
| | | 25. Effects of chemotherapy on sexuality (23%) (Knowles et al., 1999) | — |
| | | 26. The experience of other people with colorectal cancer (Salkeld et al., 2004) | — |
| | | 27. What metastatic cancer is (Northouse et al., 1999) | — |
| | | 28. Preparation for the colostomy (Northouse et al., 1999) | — |
| | | 29. How bowel function and weight can be affected by surgery (Lithner et al., 2015) | — |
| | | 30. Available support groups (Northouse et al., 1999) | — |
| | | 31. The surgical operation pre-operatively (Lithner et al., 2012) | — |
| | | 32. Genetics (Morrison et al., 2012) | — |
| | | 33. The incompatibility of some foods with patients' medical appliances (Anderson et al., 2013) | — |
| | | 34. Use of online resources (Ho et al., 2016) | — |
| | | 35. Patients' anticipated role in using self-management (Kidd, 2014) | — |
| | | 36. The possibility of sexual dysfunction and treatment options if sexual dysfunction occurs (Traa et al., 2014) | — |
| h. Health system/patient-clinician | Need for help with insufficient communication between patients and clinicians, | 1. Information that is clear/straight-forward, up-to-date, honest, unhurried, and given in a sensitive way (14-99%), especially if no curative treatment is available (29-38%) (Andersson et al., 2010; Bain and Campbell, 2000; Bain et al., 2002; Ho et | 80%; 61%-95% |

| Need domain | Operational definition | Evidence: Need for/to... | Aggregate SQS: Median; range |
|---------------|--|---|--|
| communication | satisfaction with care, participation in decision-making, preferences in communication | al., 2016; Jefford et al., 2011; Lithner et al., 2015, 2012; Morrison et al., 2012; Russell et al., 2015; Salkeld et al., 2004; Salz et al., 2014; Santin et al., 2015; Sjövall et al., 2011) | |
| | | 2. <u>Written information/publications (21-75%)</u> (Anderson et al., 2013; Boudioni et al., 2001; Ho et al., 2016; Lam et al., 2016; Li et al., 2012; Lithner et al., 2015, 2012; Salz et al., 2014), especially about treatment options/processes (72-78%) (Baravelli et al., 2009; Beaver et al., 2010; Salkeld et al., 2004) | 85%; 62%-95% 83%; 80%-86% |
| | | 3. <u>On-going communication/contact with and support from a trustworthy clinician (16-56%)</u> (Jefford et al., 2011; Lam et al., 2016; Li et al., 2012; Lithner et al., 2015, 2012; Rozmovits et al., 2004; Santin et al., 2015; Shun et al., 2014) | 86%; 61%-95% |
| | | 4. <u>Healthcare professional who treats the patient like a person, not just another case (14-32%)</u> (Lam et al., 2016; Li et al., 2012), <u>listens to what the patient has to say (94%)</u> (Salkeld et al., 2004), <u>is open and sincere, and acknowledges and shows sensitivity to patients' feelings/emotions (16%)</u> (Ho et al., 2016; Li et al., 2012; Morrison et al., 2012) and/or to <u>family/friends' feelings</u> (Morrison et al., 2012) | 93%; 91%-95% — 85%; 80%-91% — |
| | | 5. <u>Better coordination/communication among healthcare professionals (primary and secondary care) (15-68%)</u> (Bain and Campbell, 2000; Bain et al., 2002; Jefford et al., 2011; Northouse et al., 1999; Russell et al., 2015; Salamonsen et al., 2016; Santin et al., 2015) | 72%; 61%-90% |
| | | 6. <u>Follow-up visit by a specialist nurse to provide support with post-treatment concerns</u> (Baravelli et al., 2009; Beaver et al., 2010; McCaughan et al., 2012; Rozmovits et al., 2004; Salamonsen et al., 2016) | 80%; 73%-86% |
| | | 7. <u>Information customised to individual needs and abilities to handle information</u> (Bain et al., 2002; Jefford et al., 2011; Li et al., 2012; Morrison et al., 2012; Worster and Holmes, 2008) | 85%; 70%-91% |
| | | 8. <u>Quick access to information, coordinated health services, investigations and treatment (22-98%)</u> (Bain et al., 2002; Lam et al., 2016; Lithner et al., 2015; Salkeld et al., 2004; Sjövall et al., 2011) | 75%; 65%-95% |
| | | 9. <u>Participation in decision-making in a shared manner (22-72%)</u> (Bain and Campbell, 2000; Beaver et al., 1999; Russell et al., 2015; Salkeld et al., 2004) | 82%; 65%-90% |
| | | 10. <u>Post-operative follow-up/information provided by a hospital doctor (46-93%)</u> (Nikoletti et al., 2008; Papagrigoriadis and Heyman, 2003; Salz et al., 2014) | 80%; 64%-91% |
| | | 11. <u>One-to-one session for information provision with a health professional (27%) or another patient (16%)</u> (Anderson et al., 2013; Nikoletti et al., 2008; Salamonsen et al., 2016) | 73%; 62%-80% |
| | | 12. <u>Access to professional counselling if need be (9-21%)</u> (Anderson et al., 2013; Lam et al., 2016; Li et al., 2012) | 91%; 62%-95% |
| | | 13. <u>GP/family physician being informed of all developments (90%)</u> (Bain and Campbell, 2000; Salkeld et al., 2004) | 82%; 80%-83% |
| | | 14. <u>Disclosure of news on cancer recurrence (Di Fabio et al., 2008) even if there is no treatment or survival benefit (77%)</u> (Papagrigoriadis and Heyman, 2003) | 79%; 77%-81% |
| | | 15. <u>Access to quality medical care in the long-term (56%)</u> (Carlsson et al., 2010; Russell et al., 2015) | 82%; 73%-90% |
| | | 16. <u>Local health services to be available when needed (16-46%)</u> (Russell et al., 2015; Santin et al., 2015) | 76%; 61%-90% |
| | | 17. <u>Access to complementary/alternative therapies (30%)</u> (Lithner et al., 2015; Russell et al., 2015) | 78%; 65%-90% |
| | | 18. <u>Good hospital service (catering and hygiene) (9-15%)</u> (Lam et al., 2016; Morrison et al., 2012) | 90%; 85%-95% |
| | | 19. <u>Better support during transitions, i.e. post-op to adjuvant treatment; from being an active patient to becoming a survivor</u> (Ho et al., 2016; Lithner et al., 2015) | 73%; 65%-80% |
| | | 20. <u>Better educated community healthcare professionals around colorectal cancer</u> (Rozmovits et al., 2004; Sahay and Gray, 2000) | 78%; 70%-85% |
| | | 21. <u>The doctor to make the treatment decisions (78%)</u> (Beaver et al., 1999) | — |

| Need domain | Operational definition | Evidence: Need for/to... | Aggregate SQS: Median; range |
|--|------------------------|--|------------------------------|
| | | 22. Information to be provided at the point of receiving test results (62%) (Wiljer et al., 2013) | ■ |
| | | 23. Survivorship information provided during treatment (59%) (Salz et al., 2014) | ■ |
| | | 24. Complaints about care to be properly addressed (55%) (Russell et al., 2015) | ■ |
| | | 25. Post-treatment follow-up by oncologist/surgeon (50%) (Baravelli et al., 2009) | ■ |
| | | 26. Information preferably given both before (37%) and after the surgery (33%) (Nikoletti et al., 2008) | ■ |
| | | 27. Greater patient involvement in choices about the nature and setting of follow-up (Rozmovits et al., 2004) | ■ |
| | | 28. Family involvement in treatment decision-making (Salkeld et al., 2004) | ■ |
| | | 29. A holistic package of care that includes advice on diet, exercise, lifestyle and emotions provided in the short- and long-term (Anderson et al., 2013) | ■ |
| | | 30. Better prepare patients to assume responsibility for self-management (Kidd, 2014) | ■ |
| | | 31. Better patient-health professional communication about (engagement in) self-management activities (Kidd, 2014) | ■ |
| | | 32. Time to absorb/adjust to information (Lithner et al., 2015) | ■ |
| | | 33. The opportunity to ask questions (Lithner et al., 2015) | ■ |
| | | 34. Frank conversations with health professionals about the possibility of sexual dysfunction and psychosexual change (Traa et al., 2014) | ■ |
| <p>Note: For ≤ 9 needs per domain, see top 3. For 10-20 needs per domain, see top 5. For 21+ needs per domain, see top 10. SQS – Summary Quality Score; Aggregate SQS to be interpreted as follows: SQS>95% - High quality evidence; SQS=90%-95% - Very good quality evidence; SQS=80%-89% - Good quality evidence; SQS=65%-79% - Moderate quality evidence; SQS=40%-64% - Low quality evidence.</p> | | | |

Table S3. Summaries of the 54 articles reviewed.

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|--------------------------|---|--|---|-----|
| 1. Pullar et.al. (2012) | Purpose: establish dietary patterns, level of dietary advice and its impact on the behaviour of patients with colorectal cancer Context: CRC stage II, III, IV Setting: surgical or medical outpatient oncology clinics Country: New Zealand | Sample size: $n=40$ Sampling: convenience Design: Cross-sectional, exploratory, survey Time points: One Data collection technique: Patients approached by their doctors or nurses, author developed questionnaire on dietary information needs, dietary pattern and BMI category. Outcomes: Dietary information needs, dietary patterns | Demographic: 53% men, 70% >60yrs, 95% NZ European ethnicity Clinical: 50% stage III, 35% stage IV, 80% CT and S, 57% no stoma, 60% completed treatment, 37.5% with BMI 18.5-24.99, 45% with BMI 25-29.99 | 67% |
| 2. Salkeld et al. (2004) | Purpose: patients' involvement in decision-making and aspects of their treatment and outcomes Context: CRC Dukes stages A-C Setting: surgical clinics (5 surgeons at 2 hospitals) Country: Australia, Sydney | Sample size: $n=175$ Sampling: Convenience, based on colorectal cancer registry Design: Cross-sectional, exploratory, survey for tool development Time points: One Data collection technique: Posted questionnaire Outcomes: views on the treatment decision process, treatment and outcomes | Demographic: 58% men, 61% >65yrs, 40% did not complete secondary school, 78% not employed, 68% married, 58% lived in the same neighbourhood >20yrs Clinical: 33% CT, 11% RT, 59% Dukes A, 25% Dukes B, 33% family member with bowel cancer | 83% |
| 3. Sanoff et al. (2010) | Purpose: to describe elements of IDM in adjuvant CT consultations, what information is important for DM and the level of information currently delivered to patients. | Sample size: $n=35$ Sampling: Convenience, Design: Cross-sectional, exploratory, survey for tool development Time points: One Data collection technique: Tool | Demographic: 56% women, 77% <70 yrs, 77% white, 71% married, 31% with income >90K, 45% with college degree or higher. Clinical: 66% receiving | 78% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|-------------------------|--|---|---|-----|
| | Context: Colon cancer stages II-III Setting: GI medical oncology group clinic, University Country: USA, North Carolina | administered by RA Outcomes: what information is important for DM, the level of information currently delivered to patients, IDM | adjuvant CT, 69% CCI score 2 | |
| 4. Taylor et al. (2012) | Purpose: To assess individual need after colorectal cancer treatment completion; to ensure patients receive appropriate information and support during the surveillance phase of cancer care. Context: colorectal cancer survivors Setting: nurse led follow-up "end of treatment" clinic NHS Guy's and St Thomas Country: UK | Sample size: $n=18$ Sampling: convenience, consecutive Design: retrospective review of Holistic Needs Assessment Time points: one Data collection technique: assessment was completed by nurses Outcomes: HNA tool consisting of 2 parts: a distress thermometer and a concerns checklist (14 items) | Demographic: 11 men, 7 women, mean age 68 yrs Clinical: 6 >2 years of completion of treatment, 4 between 1-2 years, | 44% |
| 5. Young et al. (2010) | Purpose: To assess the acceptability, feasibility and impact of the CONNECT intervention on patients' unmet supportive care needs and quality of life. Context: Patients admitted for surgery for colorectal cancer Setting: General hospital Country: Sydney, Australia | Sample size: $n=41$ (20 Intervention Group, 21 Control Group) Sampling: Consecutive Design: Prospective, non-randomised control study Time points: Intervention: five calls in the 6 months following the patient's discharge from hospital, conducted on days 3 and 10 and then at 1, 3 and 6 months. Assessments carried out on months 1, 3 and 6 (intervention only). Data collection technique: Research nurse contacted patients and via telephone interview they completed the questionnaires. Outcomes: Unmet supportive care needs (using the SCNS), psychological distress using the distress thermometer, Quality of life (using the FACT-C) | Demographic: Intervention Group: 12 men and 8 women, mean age 66.9 yrs, 40% completed high school, 29% employed, 65% with private health insurance, 25% lived alone. Control Group: 10 men and 11 women, mean age 64.5 yrs, 38% completed high school, 33 % employed, 38% with private health insurance, 33% lived alone. Clinical: Intervention Group: 30% Dukes stage B, 30% Dukes stage C, 35% planned for adjuvant treatment, mean total FACT-C 93.8, Control Group: 33% Dukes stage B, 24% Dukes stage C, 43% planned for adjuvant treatment, mean total FACT-C 89.8. | 77% |
| 6. Zullig et al. (2012) | Purpose: to determine the level of health care related transportation difficulty reported by patients with CRC and identify patient-level determinants of experiencing transportation as a barrier to cancer care. Context: newly diagnosed VA patients with CRC in 2008. Setting: Veteran Affairs (VA) facilities Country: USA | Sample size: $n=954$ Sampling: Convenience Design: cross-sectional survey. Time points: one Data collection technique: mailed survey by post with 10\$ incentive Outcomes: Transportation difficulties derived from the Cancer Care Assessment and Responsive Evaluation Studies (C-CARES) survey. | Demographic: 100% men, mean age 68.3yrs, 76,4% white race, 82% no employed, 82,5% High School or Higher education, 50% supported by spouse and 40% by family and friends Clinical: 36% stage I, 26% stage II, symptoms reported: 53% fatigue, 51% pain, 50.5% depression. | 94% |
| 7. Beaver et al. (1999) | Purpose: to determine the decision-making role preferences and information needs for patients with colorectal cancer, and to compare these to results from studies on women with breast cancer. Context: patients with colorectal cancer (all stages) Setting: one consultant's practice, at a University hospital Country: UK | Sample size: $n=48$ Sampling: Convenience, consecutive Design: Cross-sectional Time points: One Data collection technique: Researcher attended out-patient clinics each week and approached individuals who met the entry criteria Outcomes: decision-making preference (using a decisional role preference card sort), perceived decisional role and information need (using an information needs questionnaire) | Demographic: 73% male, mean age 66.6yrs, 60% no formal qualifications, 58% social class III, 92% white British, 66% no family history of cancer 75% referred via GP Clinical: not reported | 65% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|----------------------------|---|--|--|-----|
| 8. Boudioni et al. (2001) | <p>Purpose: To describe male cancer patients' use of a national cancer information service, their information and support requests, and key predictors of these requests.</p> <p>Context: Patients with prostate or colorectal cancer placing enquiries on the CancerBACUP Information Service platform.</p> <p>Setting: Community</p> <p>Country: UK</p> | <p>Sample size: $n=379$ (patients with colorectal cancer)</p> <p>Sampling: Convenience</p> <p>Design: Cross-sectional</p> <p>Time points: One</p> <p>Data collection technique: Enquiries lodged on the CancerBACUP Information Service platform recorded on an Enquirer Record Form for every fifth enquirer.</p> <p>Outcomes: Information and support-seeking patterns.</p> | <p>Demographic: (patients with colorectal cancer) Age: 29% 50-59 y, 31% 60-69 y, 18% 70+ y; 43% male; 47% employed, 38% retired.</p> <p>Clinical: Not reported.</p> | 90% |
| 9. Klemm et al. (2000) | <p>Purpose: To describe the most common and most intense demands of illness in people with colorectal cancer.</p> <p>Context: Patients previously treated for colon, rectal or anal cancer.</p> <p>Setting: Online colorectal cancer support group.</p> <p>Country: USA</p> | <p>Sample size: $n=121$</p> <p>Sampling: Convenience</p> <p>Design: Descriptive, comparative, cross-sectional</p> <p>Time points: One</p> <p>Data collection technique: Weekly posted messages to an online colorectal support group.</p> <p>Outcomes: Demands of illness.</p> | <p>Demographic: Age: 51.9 y; 56% male; 76% married; 54% ≤ 1 y post-diagnosis, 35% 2-5 y post-diagnosis</p> <p>Clinical: 69% normal activity levels; 70% perceived illness state: cured/controlled.</p> | 80% |
| 10. Harrison et al. (2011) | <p>Purpose: To identify unmet supportive care needs of people with colorectal cancer following discharge from hospital based on the clinical audit of a cancer nurse's records.</p> <p>Context: Patients diagnosed with colorectal cancer and admitted to RPAH over a 4-year period from 01/2004 to 12/2007 and underwent a surgical procedure</p> <p>Setting: General hospital</p> <p>Country: Sydney, Australia</p> | <p>Sample size: $n=521$</p> <p>Sampling: Two trained researchers, who were blind to the data, independently reviewed nurse records and abstracted data using a standardized collection form.</p> <p>Design: Audit, retrospective</p> <p>Time points: One</p> <p>Data collection technique: Case notes maintained by a cancer nurse specialist were reviewed to identify post discharge occasions-of-service where unmet need was expressed.</p> <p>Outcomes: Types of supportive care needs identified.</p> | <p>Demographic: 219 (42%) received a post-discharge occasion-of-service where an unmet supportive care need was expressed. 129 male, mean age 63.8. 16% (81/521) of patients received one and 26% (138/521) required more than one service.</p> <p>Clinical: 114 Colon Cancer, 105 rectal cancer, 31% with stoma, mean 1.6 hospital admissions, mean 12.5 days hospital stay.</p> | 73% |
| 11. Jefford et al. (2011) | <p>Purpose: To develop and pilot test an innovative supportive care programme for people with potentially curative colorectal cancer.</p> <p>Context: Survivors of colorectal cancer.</p> <p>Setting: One cancer centre.</p> <p>Country: Australia</p> | <p>Sample size: $n=10$ (9 reported on unmet needs)</p> <p>Sampling: Convenience</p> <p>Design: Pre-test/post-test single-arm pilot study.</p> <p>Time points: Two</p> <p>Data collection technique: Validated questionnaires assessing psychological distress, unmet needs and quality of life; two satisfaction interviews.</p> <p>Outcomes: Distress, unmet needs, quality of life.</p> | <p>Demographic: Age: 55 (35-71) y; 5 male; 4 married; 5 university/college education; 6 employed; 7 urban dwellers</p> <p>Clinical: 6 ≤ 1 m since treatment completion; 7 rectal cancer; 8 stage 3A-C cancer; 7 surgery+CT+RT</p> | 72% |
| 12. Knowles et al. (1999) | <p>Purpose: To longitudinally monitor the information needs of patients with colorectal cancer.</p> <p>Context: Patients receiving adjuvant CT for surgically resected colorectal cancer.</p> <p>Setting: One oncology clinic.</p> <p>Country: UK</p> | <p>Sample size: $n=80$ (40 patients provided data over time)</p> <p>Sampling: Convenience, consecutive</p> <p>Design: Observational, repeated measures</p> <p>Time points: Four (baseline, 2 weeks, 3 months, 6 months)</p> <p>Data collection technique: Author developed information needs questionnaire; validated questionnaires for anxiety (STAI) and quality of life (EORTC QLQ-C30).</p> <p>Outcomes: Information needs, anxiety, quality of life.</p> | <p>Demographic: Age (sub sample): 59 (40-72), 62.5% married, 45% >compulsory education, 47.5% retired</p> <p>Clinical: 77% CC, 70% stage C</p> | 85% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|------------------------------|--|--|---|-----|
| 13. Macvean et al. (2007) | <p>Purpose: To test the acceptability and potential effectiveness of a program volunteer-delivered intervention to reduce the psychosocial needs of cancer patients.</p> <p>Context: Patients with colorectal cancer diagnosed within four months since diagnosis.</p> <p>Setting: A population-based registry (Victorian Cancer Registry, VCR) was used to recruit patients.</p> <p>Country: Australia</p> | <p>Sample size: $n=52$, response rate 93%</p> <p>Sampling: Convenience</p> <p>Design: Intervention study: The telephone-based intervention, called the Pathfinder Program, involves the assignment of volunteers to patients to assist them in addressing their needs as identified in questionnaires.</p> <p>Time points: two</p> <p>Data collection technique: Pathfinders made an initial call and a follow-up call to patients after each questionnaire.</p> <p>Outcomes: Supportive care needs: SCNS-59, Anxiety (HADS), Colorectal cancer related question kit (developed by researchers)</p> | <p>Demographic: Control group: $n=34$, age: 64yrs, 65% male, 68% married, 59% secondary education, 79% not working. intervention group: $n=18$ age: 64yrs, 55% male, 78% married, 55% secondary education, 72% not working.</p> <p>Clinical: Control group: 4.5 months since diagnosis, 67% stages I, IIa, 94% surgery, 44% chemotherapy, 1% radiotherapy. Intervention group: 4.8 months since diagnosis, 72% stages I, IIa, 94% surgery, 83% chemotherapy, 22% radiotherapy</p> | 46% |
| 14. Morrison et al. (2012) | <p>Purpose: To identify prevalent, salient and unmet needs amongst cancer outpatients, and to explore socio-demographic and clinical influences on expressed need.</p> <p>Context: Mixed sample of outpatients regardless of type or stage of cancer, treatment or time since diagnosis.</p> <p>Setting: One cancer treatment centre.</p> <p>Country: UK</p> | <p>Sample size: $n=110$ (24 patients with colorectal cancer)</p> <p>Sampling: Convenience</p> <p>Design: Cross-sectional, descriptive survey</p> <p>Time points: One</p> <p>Data collection technique: Author-developed, postal questionnaire.</p> <p>Outcomes: Supportive care needs (psychological, treatment/care, informational, practical, interpersonal, experiential).</p> | <p>Demographic: (Overall sample) Age: 67 ± 11 (32-90) y; 55% male.</p> <p>Clinical: 33% urology, 24% colorectal, 24% breast, 8% gynaecology, 7% haematology, 6% head and neck; Time since diagnosis: 23 m; Treatment: 30% surgery only, 36% surgery plus CT/RT, 34% no surgery.</p> | 85% |
| 15. Holm et al. (2012) | <p>Purpose: To investigate associations between cancer survivors' sex, age, and diagnosis in relation to their (1) need for rehabilitation, (2) participation in rehabilitation activities, and (3) unmet needs for rehabilitation in a 14-month period following date of diagnosis.</p> <p>Context: Patients diagnosed with cancer including patients with colorectal cancer 14 months after diagnosis</p> <p>Setting: All patients residing in Central or Southern Denmark</p> <p>Country: Denmark</p> | <p>Sample size: $n=3439$ of which $n=522$ (15.2%) colorectal cancer</p> <p>Sampling: Population based</p> <p>Design: Cohort study</p> <p>Time points: one</p> <p>Data collection technique: Following identification by the administrative sampling procedure, each patient's GP was mailed a questionnaire to confirm that a cancer was diagnosed. A questionnaire developed for the purposes of the study was then sent to patients via post.</p> <p>Outcomes: Needs, present and unmet</p> | <p>Demographic: For responders: 57% women (total sample)</p> <p>Clinical: Not available</p> | 86% |
| 16. McCaughan et al. (2012) | <p>Purpose: To compare the male and female experience of a shared cancer – reporting findings from extended survivorship.</p> <p>Context: newly diagnosed patients with CRC</p> <p>Setting: regional Cancer Centre</p> <p>Country: Northern Ireland</p> | <p>Sample size: $n=38$</p> <p>Sampling: purposive considering gender, age, treatment and the presence of stoma</p> <p>Design: longitudinal qualitative</p> <p>Time points: 4: after surgery (T1), end of CT (T2), 6 months post CT (T3), 12 months post CT (T3) – reporting findings from T3-T4.</p> <p>Data collection technique: one-to-one semi-structured interviews</p> <p>Outcomes: for T3, T4: experiences since treatment completion – change in coping strategies</p> | <p>Demographic: 24 male, 14 female, Age (SD) 60 (12.15), 82% married, 53% not working</p> <p>Clinical: 47% Surgery + CT</p> <p>Recruitment rates: 38(T1), 32(T2), 24(T3), 16(T4)</p> | 75% |
| 17. Northhouse et al. (1999) | <p>Purpose: 1. To describe the reaction of patients and spouses to the colon cancer diagnosis 2. To identify lifestyle changes that they encountered, 3. Identify greatest concerns after diagnosis, 4. Determine satisfaction for information 5. Identify ways hcp to assist people to cope with illness and treatment</p> | <p>Sample size: $n= 30$ patients (and spouses)</p> <p>Sampling: convenience</p> <p>Design: descriptive, cross-sectional</p> <p>Time points: 1</p> <p>Data collection technique: semi-structured interviews</p> <p>Outcomes: concerns, coping styles, lifestyle changes</p> | <p>Demographic: 80% men, age 63 (SD: 12.5), education: 12 ys, 60% on retirement, average marriage duration: 35 years</p> <p>Clinical: 40% had colostomy, 67% comorbidities (hypertension, heart disease), 66.7% no family history of colon cancer, 27% metastatic, 20% CT, 34% CT and RT</p> | 70% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|--------------------------------------|---|---|---|-----|
| | Context: mixture of early diagnosis/survival Setting: metropolitan regions Country: USA | | | |
| 18. Papagrigroriadis & Heyman (2003) | Purpose: To investigate the views and experiences of British patients with colorectal cancer about the follow up process; to assess their attitudes towards abandoning hospital follow up, or substituting less medically intensive policies. Context: Post- surgery patients with colorectal cancer Setting: One outpatient surgical clinic Country: UK | Sample size: $n=95$ Sampling: Convenience Design: Survey Time points: One Data collection technique: postal survey Outcomes: patient's views and experiences about follow-up visits/ investigations | Demographic: Not provided Clinical: 63% had surgery within the past 3 years from the study, 45% had received adjuvant chemotherapy, 21% with stoma, | 81% |
| 19. Sahay et al. (2000) | Purpose: To explore patients' experiences of colorectal cancer Context: at least 6 months post diagnosis Setting: one cancer centre Country: Canada (Toronto) | Sample size: $n=20$ Sampling: Theoretical, consecutive Design: Exploratory, cross-sectional, no methodology stated Time points: one Data collection technique: Interviews – Structured interviews Outcomes: Patients' experiences, meanings, perceptions of illness | Demographic: Age: 65 (48-87); 18 married with children, 45% retired, Clinical: At the time of interview time since diagnosis: 6 months – 7 years, 100% post-surgery, 50% relapsed cancer | 70% |
| 20. Sjövall et al. (2011) | Purpose: To investigate how the life situation of persons with advanced colorectal cancer and their partners is affected by living with the disease and its treatment Context: Patients with advanced colorectal cancer, having received palliative chemotherapy Setting: One oncology unit Country: Sweden | Sample size: $n=12$ patients, 9 spouses Sampling: Maximum variation Design: Qualitative Time points: One Data collection technique: The nurse who administered the treatment provided written and verbal information to possible participants. If the person with cancer accepted, he/she was asked for permission for the partner to be asked about participation. The person with cancer and the partner were interviewed separately, Outcomes: Experiences of patients and spouses of colorectal cancer and its treatment | Demographic: The median age among the persons with cancer was 60 years (range 40-78), and median time since diagnosis was 18 months (range 6-48). There were seven men and five women among the patient' sample, and six women and three men among the partners' sample. Clinical: not available | 75% |
| 21. Rozmovits et al. (2004) | Purpose: To identify the range of patient pathways following surgery for colorectal cancer and explore patients' needs and preferences for follow-up. Context: Patients with colorectal cancer (all stages) Setting: 50 hospitals taking part in the Colorectal Cancer Services Collaborative Country: UK | Sample size: $n=39$ Sampling: Maximum variation sampling (no specific parameters provided) Design: Qualitative Time points: One Data collection technique: Sample came from a wider across the UK survey in 50 hospitals. People who wished to volunteer returned a contact slip direct to the researcher, who then made contact to arrange the interview. Outcomes: Patients' needs and follow-up attitudes. | Demographic: Age: 60 (20 male) Clinical: 21% Dukes stage B, 54% did not know their stage. 61% had a stoma, 54% had a combination of Surgery and CT/RT | 85% |
| 22. Worster & Holmes (2008) | Purpose: To explore patients' experiences following surgery for colorectal cancer and offer guidance for care in the weeks following surgery. Context: Post-surgical patients with colorectal cancer Setting: One gastrointestinal surgical ward in a district general hospital Country: UK | Sample size: $n=20$ Sampling: Purposive: patients who had undergone surgery for the removal of a colorectal tumour with end-to-end anastomosis; those with stoma were excluded. Design: Cross-sectional, phenomenological Time points: one Data collection technique: Participants were approached | Demographic: 100% Caucasian, 10 men, 10 women, age range: 50 - 82 yrs. Clinical: 19 through GP referral. 100% undergone surgery to remove a portion of bowel with end-to-end anastomosis. None with stoma. | 85% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|-----------------------------|---|---|---|-----|
| | | following admission and before surgery; agreement to interview was sought. They were then contacted 4 weeks after discharge. Interviews were conducted in patients' homes. Outcomes: patients' perspectives on their experiences | | |
| 23. Bain & Campbell (2000) | Purpose: To explore the perspectives of the patients receiving treatment for colorectal cancer, to compare attitudes and priorities in rural and urban areas Context: any stage except for terminal stage of illness Setting: Out-patient clinic for colorectal cancer patients, and chemotherapy in-patient clinic. Country: UK (Scotland) | Sample size: $n=22$ patients (and 10 spouses) Sampling: Sampling frame (variables: rural/ urban, treatment type) Design: exploratory, cross-sectional Time points: one Data collection technique: focus group interviews Outcomes: differences in experiences based on rural/ urban area | Demographic: Age: 36% >70 yrs, 36% <60 yrs, 50% urban Clinical: various stages with colorectal cancer, various treatments (does not specify) | 80% |
| 24. Bain et al. (2002) | Purpose: To explore how patients with colorectal cancer perceive their care. To compare the views and experiences of outlying patients to those of patients living in urban areas. Context: Patients with colorectal cancer stages I-III. Setting: Oncology and surgical outpatient clinics, chemotherapy in-patient and out-patient clinics. Country: UK - Scotland | Sample size: $n=95$ (61 patients, 34 relatives) in this paper $n=63$: 39 patients and 24 relatives Sampling: Purposive Design: Qualitative, using a mixture of focus groups and 1-1 interviews with patients and relatives Time points: One Data collection technique: Patients/ relatives were interviewed at their homes, preferable separately using an interview schedule devised from the focus groups. Outcomes: Care perceptions | Demographic: not reported Clinical: Not reported | 70% |
| 25. Andersson et al. (2010) | Purpose: To describe the experience of women living with a colostomy as a result of rectal cancer Context: women who had had rectal cancer had a colostomy surgery and still working Setting: Hospital (surgical ward) Country: Sweden | Sample size: $n=5$ Sampling: purposive sample Design: Qualitative – thematic content analysis Time points: One Data collection technique: interviews of the women were based on a narrative approach using an interview guide. Outcomes: patient experiences of living with a stoma | Demographic: ages from 60–65 years, 4 lived together with a partner. 3/5 the women had returned to their usual work, Time since diagnosis: 1–6 years. Clinical: not available | 80% |
| 26. Baravelli et al. (2009) | Purpose: To survey key stakeholders in the care of people with colorectal cancer (survivors, primary care providers and hospital-based healthcare professionals) regarding follow-up and survivorship care plans. Context: CRC survivors Setting: Cancer centre Country: Australia | Sample size: $n=20$ (part 1), $n=12$ (part 2) Sampling: Convenience Design: Mixed methods, sequential Time points: one Data collection technique: self-reported questionnaire and interviews Outcomes: survivorship care plan | Demographic: Part 1: 65% men, 63yrs (SD= 31-81), 35% primary/secondary school, 40% vocational education, 90% married Part 2: 58% men, 63yrs (SD= 47-77), 42% primary/secondary school, 42% vocational education, 83% married, Clinical: Part 1: 80% with rectal cancer, 40% stage II – 45% Stage III, Part 2: 75% with rectal cancer, 58% stage II – 34% Stage III | 86% |
| 27. Beaver et al. (2010) | Purpose: To explore patient perceptions of their experiences of follow-up care after treatment for colorectal cancer Context: CRC patients post treatment Setting: Hospital clinics (vague) Country: UK | Sample size: $n=27$ Sampling: Purposive Design: Exploratory qualitative study Time points: one Data collection technique: In-depth interviews Outcomes: Patient experiences | Demographic: 52% men, 72 yrs (SD= 59-86), 44% >24 months since diagnosis Clinical: 55.6% colon cancer, 100% surgery, 25.9% CT, 48% no stoma, 41% stoma | 80% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|----------------------------|--|---|---|-----|
| 28. Browne et al. (2011) | <p>Purpose: To explore colorectal cancer patients' experiences of psychosocial problems and their management in primary and specialist care.</p> <p>Context: Patients with CRC</p> <p>Setting: 3 hospitals</p> <p>Country: UK (Scotland)</p> | <p>Sample size: $n=24$</p> <p>Sampling: Part of a larger study, purposive, maximum variation sample (sampling frame: age, sex, socioeconomic status, level of coexisting morbidity)</p> <p>Design: Longitudinal qualitative study</p> <p>Time points: two: at diagnosis (T1), 12 months post diagnosis (T2)</p> <p>Data collection technique: In-depth interviews</p> <p>Outcomes: management of needs in primary and secondary care.</p> | <p>Demographic: 62.5% women, aged 34-84 yrs, 56% retired, 42% with no formal educational level.</p> <p>Clinical: 37.5% Dukes stage B, 21.2% stage C, 79% no stoma</p> | 90% |
| 29. Carlsson et al. (2010) | <p>Purpose: To assess concerns and health-related quality of life before surgery and during the first 6 months following ostomy surgery in patients with rectal cancer.</p> <p>Context: Patients scheduled to undergo elective surgery for rectal cancer including a temporary loop ileostomy or a permanent colostomy.</p> <p>Setting: One university hospital</p> <p>Country: Sweden</p> | <p>Sample size: $n=57$</p> <p>Sampling: Convenience</p> <p>Design: Descriptive, observational, repeated measures</p> <p>Time points: Four (pre-operatively and at 1, 3 and 6 months post-surgery)</p> <p>Data collection technique: Validated questionnaires for bowel disease concerns (RFICP) and quality of life (SF-36).</p> <p>Outcomes: Patient concerns and health-related quality of life over time.</p> | <p>Demographic: Median age: 66 (30-87) years; 61% males; 81% partnered.</p> <p>Clinical: 77% colostomy; 75% RT; 42% CT</p> | 73% |
| 30. Cha et al. (2012) | <p>Purpose: To pilot collection of data to describe the dietary intakes and dietary patterns of CRC patients in the Auckland region, to investigate what the current information resources are for CRC patients in the region, and patient satisfaction with these resources.</p> <p>Context: Patients with CRC with surgical resection (with curative intent) of their tumour in the last 1-4 months</p> <p>Setting: three district health boards in Auckland regions</p> <p>Country: New Zealand</p> | <p>Sample size: $n=29$ (73% response rate)</p> <p>Sampling: Convenience</p> <p>Design: Small cross-sectional survey using a modified version of the qualitative food frequency questionnaire (FFQ)</p> <p>Time points: One</p> <p>Data collection technique: Eligible participants were identified and approached by local clinicians. A study information sheet, consent form, decline participation form, questionnaire and a reply-paid envelope were posted to each of the patients whose details have been provided to the researchers. Additional clinical data on participant co-morbidities, the extent of disease (disease stage) and treatment received were obtained from the participants' medical records if specific consent was given.</p> <p>Outcomes: Dietary patterns, information needs on diet</p> | <p>Demographic: 20 men, 9 women, most commonly aged 70+. 69% were New Zealand/European, 41% ex-smokers, 7% were current smokers. 67% reported taking either none or less than 5 standard alcoholic drinks per week.</p> <p>Clinical: No information provided</p> | 86% |
| 31. Di Fabio et al. (2008) | <p>Purpose: To explore patients' self-reported quality of life, sexual dysfunction and needs during long-term follow-up, and surgeons' awareness of their patients' needs.</p> <p>Context: Patients with non-metastatic and/or non-recurrent colorectal cancer having undergone surgery ≥ 1 year earlier.</p> <p>Setting: One surgical department</p> <p>Country: Italy</p> | <p>Sample size: $n=62$</p> <p>Sampling: Convenience</p> <p>Design: Cross-sectional, descriptive, observational</p> <p>Time points: One</p> <p>Data collection technique: Validated questionnaires on quality of life (EORTC QLQ-C30 and CR38), and author-developed questions on perceived needs.</p> <p>Outcomes: Quality of life, patient needs, surgeon awareness of patients' needs</p> | <p>Demographic: Mean age: 61.6 ± 9.3 (45-77) years; 58% Male; 71% High school education only</p> <p>Clinical: Disease site: 66% Colon, 34% Rectum; Disease stage: 22% I, 39% II, 39% III; 66% Adjuvant treatment; Time since surgery: 37.2 ± 18.8 (14-74) years</p> | 77% |
| 32. Dunn et al. (2006) | <p>Purpose: To provide descriptive data on the quality of life and psychosocial variables most</p> | <p>Sample size: Interviews $n=15$, Focus groups $n=7$ (5 patients and 2 spouses)</p> <p>Sampling: Criterion sampling</p> | <p>Demographic: none provided</p> <p>Clinical: none provided</p> | 70% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|-------------------------------|---|--|--|-----|
| | salient to colorectal cancer patients. Context: Patients diagnosed with colorectal cancer within the past 18 months Setting: One surgical department, local cancer support programs and accommodation centres (unclear how many) Country: Australia | Design: Qualitative, between-method (or across-method) triangulation, cross-sectional Time points: One Data collection technique: Interviews and focus groups. Outcomes: quality of life, psychosocial variables | | |
| 33. Galloway & Graydon (1996) | Purpose: To determine the relationships between uncertainty, symptom distress, and discharge information needs in individuals after a colon resection for cancer. Context: Post-operative patients with colon cancer Setting: Three hospitals Country: Canada | Sample size: $n=40$ (T1), $n=28$ (T2) Sampling: Convenience Design: A prospective non-experimental correlation design Time points: two: <72h post hospital discharge and 4 weeks after hospital discharge. Post-discharge interviews were not done in 12 subjects due to refusal ($n=9$), inability to contact ($n=1$), death ($n=1$), and reoperation with formation of a colostomy ($n=1$). Data collection technique: Completion of questionnaires. Patients who met the sample criteria were identified by surgical nurses on the inpatient units, and, if the patient agreed, a research assistant gave a verbal explanation of the study and written consent was obtained from those who were willing to participate in the study. Outcomes: information needs, symptom distress, uncertainty | Demographic: 20 men, 20 women, mean age: 66.2 yrs (SD = 11.62). 65% married, 15% widowed. 15 completed college or university, 24 subjects with lower education. Clinical: Hemicolectomy ($n=16$), anterior resection ($n=10$), sigmoidectomy ($n=7$), colectomy ($n=4$). Length of hospitalization 15.6 days (SD = 9). 72.5% had no postoperative complications, 12% wound infection. | 75% |
| 34. Hansen et al. (2013) | Purpose: To explore whether patient-perceived unmet needs of rehabilitation during the cancer trajectory are associated with decreased quality of life. Context: Population-based cohort of patients diagnosed with cancer. Setting: Registry entries within two country regions Country: Denmark | Sample size: $n=3,439$ ($n=522$ colorectal cancer) Sampling: Population-based Design: Cross-sectional survey Time points: One Data collection technique: Validated questionnaires on quality of life (EORTC QLQ-C30) and psychological distress (POMS-SF), and author-developed questions on perceived unmet needs. Outcomes: Quality of life, psychological distress | Demographic: 8% 18-44 years, 45% 45-64 years; 47% 65+ years; 57% Female Clinical: 28% Breast cancer, 15% Colorectal cancer, 15% Prostate cancer, 7% Malignant melanoma, 7% Gynaecological cancer, 5.5% Lung cancer | 90% |
| 35. Husson et al. (2012) | Purpose: To measure the perceived level of, and satisfaction with, information received by patients with metastatic colorectal cancer versus those with non-metastatic colorectal cancer. Context: Patients diagnosed with colorectal cancer between 2002 and 2007. Setting: National Cancer Registry Country: The Netherlands | Sample size: $n=1,159$ Sampling: Population-based Design: Descriptive, cross-sectional survey Time points: One Data collection technique: Postal distribution of validated questionnaires on information provision (EORTC QLQ-INFO25), health status (SF-36), anxiety and depression (HADS), and illness perceptions (B-IPQ). Outcomes: Information provision and satisfaction; health status; anxiety and depression; illness perceptions. | Demographic: Age: 69.2 ± 9.7 y; 57% male. Clinical: Stage at diagnosis: 39% II, 29% III, 6% IV; Time since diagnosis: 3.5 ± 1.5 y; 52% surgery only; 42% surgery plus CT/RT. Stage at survey: 12% (139) IV. | 82% |
| 36. Jorgensen et al. (2012) | Purpose: To explore how unmet needs differ by age over the 3 months following colorectal cancer surgery. Context: Patients with colorectal cancer scheduled for curative surgery. | Sample size: $n=57$ Sampling: Convenience, consecutive Design: Secondary analysis of two RCT datasets, descriptive, repeated-measures Time points: Three (baseline, 1 and 3 months post-discharge) | Demographic: Younger group – Mean age: 50.9 ± 11.6 years; 50% male; 71% at least high school education; 68% employed; 18% lived alone. Older group – Mean age: 74.3 ± 6.3 years; 60% male; | 86% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|----------------------------|---|--|---|-----|
| | Setting: One hospital. Country: Australia | Data collection technique: Validated questionnaire for supportive care needs (SCNS-SF34) Outcomes: Supportive care needs. | 31% at least high school education; 17% employed; 48% lived alone. Clinical: Younger group – 46% colon, 46% rectal; 25% Duke's A, 32% Dukes B, 29% Dukes C; 11% metastatic disease; 50% adjuvant treatment; 43% ≥ 1 comorbid illnesses. Older group – 45% colon, 41% rectal; 21% Duke's A, 21% Dukes B, 34% Dukes C; 7% metastatic disease; 24% adjuvant treatment; 69% ≥ 1 comorbid illnesses. | |
| 37. Li et al. (2013) | Purpose: To examine the prevalence of supportive care needs in Chinese breast and colorectal cancer patients to identify prevalence and correlates of unmet needs. Context: Patients with early-stage (0-II) breast or colorectal cancer diagnosed within the past 2 years during follow-up consultations. Setting: One hospital. Country: China | Sample size: $n=104$ (colorectal cancer) Sampling: Convenience Design: Cross-sectional, descriptive, correlational Time points: One Data collection technique: Validated questionnaires for supportive care needs (SCNS-SF34), psychological distress (HADS), patient satisfaction (CPSQ); and symptom distress (MSAS-SF). Outcomes: Unmet supportive care needs. | Demographic: Mean age: 66.5 ± 9.6 (45-84) years; 56% male; 69% married; 35% primary education; 57% retired. Clinical: Time since diagnosis: 7.9 ± 5.0 months; 80% no active treatment. | 91% |
| 38. Nikolett et al. (2008) | Purpose: To determine the information needs of patients with colorectal cancer in relation to bowel management. Context: Survivors of colorectal cancer within 6 and 24 months after sphincter-saving surgery. Setting: Two teaching hospitals and two colorectal surgeons. Country: Australia | Sample size: $n=101$ Sampling: convenience, consecutive Design: Cross-sectional, descriptive, observational, retrospective Time points: One Data collection technique: Author-developed survey including fixed-response and open-ended questions Outcomes: Information needs (appetite, digestion, and bowel function; daily activities; social interactions; self-care practices) | Demographic: Mean age: 66.2 ± 10.0 (40-88) years; 70% males; 85% lived in metropolitan area; 60% high school education; 72% married; 66% retired; 79% lived with spouse or family. Clinical: 56% surgery only; 42% CT; 18% RT | 80% |
| 39. Shun et al. 2014 | Purpose: To explore the association between supportive care needs (SCN) and type D personality. To identify personality traits and influence on SCN of pts. with CRC. Context: CRC Setting: Oncology and surgical outpatient clinics at a medical centre or surgical wards. Country: Taiwan | Sample size: $n=277$ Sampling: convenience Design: Cross-sectional, correlational survey. Time points: Data collection technique: Not stated who approached pts. Questionnaires (4 established instruments DCF, CCF & background info form) completed by research assistants Outcomes: Levels unmet SCN highly associated with type D personality. HCPs should assess personality traits -> educational interventions and should supply enough information. | Demographic: mean age 58 (SD 11), 57% male (also tabulated other items eg. religion, marital status) Clinical: 78% colon, staging – 13% stage I, 26% II, 39% III, 22% IV. 48% completed treatment, 90% 1 st diagnosis, 10% had colostomy. KPS <1% 50, 1% 70, 4% 80, 30% 90, 65% 100. | 86% |
| 40. Traa et al. (2013) | Purpose: To a) examine sexual health care needs according to pts., partners (ptr.) and HCPs. b) Identify factors that facilitate / impede quality of sexual health care Context: During and after treatment for CRC (pt. or ptr of eligible pt.) Setting: Three hospitals Country: Netherlands | Sample size: $n=21$ Sampling: purposive Design: Qualitative (focus groups), questionnaire Time points: One Data collection technique: Eligible pts. / ptrs approached by 1 researcher. Selected on age/sex/tumour type (if appropriate). HCPs approached by 2 other members of research team. Focus groups (separate for HCP, male pt, female pt., male ptr, female ptr) Questionnaire & 10 point scale | Demographic: 12/21 pts. male. Mean age 63.2 (47-75). Educational & marital status stated All Caucasian Clinical: 10/12 colon, 11/21 rectum 8/21 no stoma, 6/21 temporary stoma, 7/21 definitive stoma (split by sex) | 60% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|------------------------------|--|---|--|-----|
| | | Outcomes: Recommendations for research and clinical practice. Identified a need for pt.-tailored sexual healthcare – complexities of providing and receiving same. | | |
| 41. Russell et al. (2015) | Purpose: To describe 1) psychological morbidity and quality of life in CRC patients at treatment completion, with reference to the general population, 2) CRC-specific symptoms and problems and supportive care needs and also 3) the association between psychological morbidity, quality of life and CRC-specific symptoms and problems Context: CRC stage I, II or III, completed treatment with curative intent, within 6 months post-treatment, (comparative sample is sample of general population) Setting: Outpatient clinic at private and public hospitals from different regional and metropolitan areas Country: Australia | Sample size: n=152 Sampling: purposive sampling Design: data from multi-site RCT (described elsewhere (refs 18,19) Time points: One (post-treatment) Data collection technique: Patients approached by data manager, clinical details from medical records, no other details reported Outcomes: Brief symptom inventory (BIS-18), EORTC-30, EORTC-29, Cancer survivors' unmet needs measure (CaSUN), (Data from general population for EORTC-30 obtained from University of Sydney) | Demographic: Male n=77 (50.7%), Age (mean 63.9, SD 11.0), Area: Major city (n=75, 49.3%), Regional (n=76, 50%). Remote/very remote (n=1, 0.7%); Married n=107, 70.4%; Country of birth Australia n=124, 81.6%), Employment (working n=43, 28.3%, retired n=69, 45.4%, other n=40, 26.4%); Clinical: Colon cancer n=82, 53.9%, Rectal cancer n=57, 37.5%, overlapping n=15, 9.9%; Stage: I n=12, 7.9%, II n=36, 23.7%, III n=104, 68.4%; Treatment: Surgery n= 13, 8.6%, Surgery plus chemo n=92, 60.5%, Surgery plus chemo plus radio n=47, 30.9% | 90% |
| 42. Salamonsen et al. (2016) | Purpose: How did the participants illustrate their individual patient pathways? What did the participants describe as the most important health and life events affecting their patient pathways? What were the participants' experiences from the public health care system? Context: rectal cancer Tumor–Node–Metastasis stage I–III (Dukes A–C), completed primary treatment Setting: University Hospital Norwich, Country: Norway | Sample size: 10 Sampling: purposive sampling-sampling until data saturated Design: qualitative, longitudinal study Time points: Data collection technique: patients identified from electronic patient record, sent invitation letters, Outcomes: 1 qualitative in-depth interview with each patient, diaries over 4 periods of 3 months- or semi-structured interviews with people who did not complete diaries, visual illustrations of patient pathways in workshops with patients | Demographic: Female n= 6, Median Age = 61 (range 53-68), Education: secondary education n=3, high school or equivalent n=2, trade/vocational diploma n=3, bachelor degree=n=0, masters/professional degree n=2, Marital status: married or living with partner n=7, Living status: Alone n=3, with children n=0, with spouse/partner n=5, with spouse/partner and children n=2, Work: unknown: n=1, full-time n=2, part-time n=1, self-employed n=0, Unemployed n=0, retired n=1, disability income n=3 Clinical: None reported | 73% |
| 43. Walling et al (2016) | Purpose: To assess prevalence of patient-reported unmet needs for management of common cancer symptoms (pain, fatigue, depression, nausea/vomiting, cough, dyspnoea, diarrhoea) in patients newly diagnosed with lung or colorectal cancer. To evaluate how unmet needs for symptom management are associated with patient-rated physician communication quality? Context: based on a national cancer survey involving patients at all stages of disease Setting: patients recently diagnosed with colorectal or lung cancer (3-6 months post-diagnosis) Country: USA | Sample size: 3011 Sampling: Based on data from the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS), included only patients who were alive and able to complete sections 8 and 9 of the CanCORS baseline survey, which addressed symptom prevalence and management Design: cross-sectional, observational study Time points: One Data collection technique: Survey questionnaires – unclear whether self-administered or facilitated by 'interviewer'. Range of questionnaires used to explore each particular symptom. Outcomes: proportion of unmet needs for symptom management. Relationship between unmet needs for symptom management and quality of physician communication. | Demographic: Male 53.3%, female 46.7%, ages: 21-59 33.9%, 60-69 29.2%, 70-79 26.3%, >80 10.6%. Clinical: Patients with early lung cancer 23.9%, late lung cancer 20.6%, early colorectal cancer 44.7% and late colorectal cancer 10.8%. | 70% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|---------------------------|--|--|--|-----|
| 44. Wiljer et al (2015) | <p>Purpose: To elicit the opinions of patients with CRC to capture their needs and preferences for information and support during the pre-diagnostic phase</p> <p>Context: Colorectal cancer survivors</p> <p>Setting: Ambulatory clinics at three cancer centres</p> <p>Country: Canada</p> | <p>Sample size: 82</p> <p>Sampling: A consecutive series of eligible identified through hospital medical records</p> <p>Design: prospective survey design</p> <p>Time points: time 1 (T1) assessment between 2–4 months post-diagnosis repeated at time 2 (T2) 6 months later</p> <p>Data collection technique: Questionnaires: Support Care Needs Survey (SCNS-LF59), Abbreviated Information Satisfaction Questionnaire (ISQ), Service Needs Questionnaire (SNQ), the EORTC QLQ-C30</p> <p>Outcomes:</p> | <p>Demographic: female older group n=84, female younger group n=150, male older group n=106, male younger group n=54</p> <p>Clinical: patients with lung, colorectal, breast or prostate cancer</p> | 70% |
| 45. Lithner et al. (2015) | <p>Purpose: To explore patients' experiences of information and their information needs post-colorectal cancer surgery</p> <p>Context: Adult patients who had surgery for colorectal cancer without receiving a stoma</p> <p>Setting: Patients' homes</p> <p>Country: Sweden</p> | <p>Sample size: 16</p> <p>Sampling: From an initial sample of 100 consecutive patients (from a larger prospective study), 16 patients were selected purposefully</p> <p>Design: Qualitative content analysis of semi-structured interviews</p> <p>Time points: Two - the initial period at home and after the postoperative visit when the results from the tissue samples and further treatment had been discussed</p> <p>Data collection technique: 31 interviews were performed with 16 patients: the first 1-2 weeks after discharge and the second 5-7 weeks after discharge.</p> <p>Outcomes: patients experience of the information received and what their information needs were.</p> | <p>Demographic: 62.5% men, Mean age 66.6 SD 10.1, range 50-82; 15 lived with spouse/partner, 1 with adult child</p> <p>Clinical: 10 had comorbidities like heart or lung disease, diabetes or orthopaedic disease; 8 were offered chemotherapy</p> | 65% |
| 46. Ran et al. (2016) | <p>Purpose: To investigate the quality of life, self-care knowledge access, and self-care needs of colorectal cancer patients after colostomy</p> <p>Context: colorectal cancer patients one month after temporary or permanent colostomy</p> <p>Setting: Hospital stoma clinic</p> <p>Country: China</p> | <p>Sample size: 142</p> <p>Sampling: a convenience sample</p> <p>Design: Descriptive cross-sectional survey</p> <p>Time points: One</p> <p>Data collection technique: 142 print surveys were distributed, and 142 were returned. The patients answered the questions read by the interviewer or completed the questionnaire by themselves</p> <p>Outcomes: Chinese version of WHOQOL-BREF, (0= worst, 100= best quality of life); peristomal skin status, daily stoma pouch care, comprehensiveness of self-care knowledge from the hospital, methods available to obtain self-care knowledge and skills, and preference of self-care knowledge</p> | <p>Demographic: Male 72.5%; Mean age 54.6 SD 13.8; Married 95.7% Widow 2.1%, Divorced 1.4%, Single 0.7%, Secondary school or above 54.4%,</p> <p>Clinical: family history of CRC 7.7%</p> | 50% |
| 47. Salz et al. (2014) | <p>Purpose: To better understand whether CRC survivors who do not receive SCPs are equipped to communicate relevant information to primary care providers and manage their own care. We also aimed to assess preferences for the content, format, and delivery of SCPs.</p> <p>Context: Tumour site colon, rectum or both; CRC stage I, II, III.</p> | <p>Sample size: 175</p> <p>Sampling: Purposive</p> <p>Design: Survey</p> <p>Time points: One - Participants completed treatment 6 to 24 months before the interview and had not received a Supportive Care Plan.</p> <p>Data collection technique: Author-developed questionnaire. 5-point Likert scale used for items included. Focused on 16 topics of information.</p> <p>Outcomes: We evaluated whether</p> | <p>Demographic: 51% male, 86% white, mean age at diagnosis = 57, mean at survey = 59</p> <p>Clinical: 58% colon, 42% rectum, 1% both. 98% surgery, 75% chemo, 30% radio. 20% stage I, 27% stage II, 53% stage III.</p> | 64% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|--------------------------|---|---|---|-----|
| | <p>Setting: 2 hospitals in the New York metropolitan area: 1) a private tertiary not-for profit comprehensive cancer center; 2) a comprehensive cancer center at a public hospital.</p> <p>Country: USA</p> | <p>survivors knew their treatment history (10 topics), whether they understood ongoing risks (four topics), and their preferences for receiving 16 topics of survivorship information.</p> | | |
| 48. Santin et al. (2015) | <p>Purpose: To identify the needs of CRC survivors (via a survey-based quantitative assessment) and the relationship between need and QoL in order to inform practitioners and service providers about the issues faced by individuals living with and beyond CRC.</p> <p>Context: Patients with a diagnosis of CRC at 18+, were not receiving active treatment or end of life care for cancer and had no cognitive impairment.</p> <p>Setting: Cross-sectional sample identified from Northern Ireland Cancer Registry, identified participants' GPs were sent questionnaire packs and disseminated from there.</p> <p>Country: Northern Ireland</p> | <p>Sample size: 124</p> <p>Sampling: Questionnaires were sent to a randomly selected sample of 600 CRC survivors.</p> <p>Design: Postal questionnaires.</p> <p>Time points: One</p> <p>Data collection technique: Questionnaires were posted to participants.</p> <p>Outcomes: Cancer Survivors Unmet Needs survey (CaSUN) & Quality of Life in Adult Cancer Survivors Scale (QLACS).</p> | <p>Demographic: n=52 female, mean average age = 52, n=91 married, n=33 not married. Urban n=80, Rural n=44. Social Deprivation – Most deprived n=43; moderate n=54; Least n=27.</p> <p>Clinical: Dukes Staging A n=15; Dukes Staging B n=51; Dukes Staging C n=25; Dukes Staging D n=3; Unknown n=30. Time since diagnosis 2-5 years n=64; 6-10 years n=39; 11+ n=21.</p> | 61% |
| 49. Ho et al. (2015) | <p>Purpose: To identify the specific concerns of colorectal cancer survivors on key survivorship domains, as well as short-/long-term needs.</p> <p>Context: CRC stage II and III; survivorship</p> <p>Setting: Community-dwelling survivors identified through a provincial-based cancer registry, the British Columbia Cancer Registry</p> <p>Country: Canada</p> | <p>Sample size: 30</p> <p>Sampling: Convenience, one-time mailed invitation packages</p> <p>Design: Cross-sectional, exploratory</p> <p>Time points: One</p> <p>Data collection technique: Opt-in method; focus group, audio-recorded interviews with use of a semi-structured interview guide</p> <p>Outcomes: Survivorship care domains (physical functioning, psychological well-being and social relationships), informational and supportive care needs.</p> | <p>Demographic: Median age 60 (range 41-75) years; 16 men</p> <p>Clinical: 93% stage III; 57% colon cancer, 43% rectal cancer</p> | 80% |
| 50. Kidd (2012) | <p>Purpose: To understand cues and barriers to people's engagement in self-management during chemotherapy for CRC.</p> <p>Context: Stage B/C (Dukes); active chemotherapy</p> <p>Setting: One cancer centre</p> <p>Country: UK</p> | <p>Sample size: 11</p> <p>Sampling: Convenience, consecutive</p> <p>Design: Prospective, baseline and follow-up</p> <p>Time points: Two</p> <p>Data collection technique: Qualitative, one-to-one, semi-structured interviews at start of treatment (T1) and 6 months later (T2).</p> <p>Outcomes: Self-management engagement</p> | <p>Demographic: Median age 69 (range 49-76) years; 8 men; 8 lived with partner</p> <p>Clinical: 10 PS=0; 10 Stage C (Dukes); 7 with 1-2 comorbid illnesses</p> | 80% |
| 51. Lam (2016) | <p>Purpose: To determine supportive care needs trajectories over the first year following CRC surgery. To identify factors differentiating these trajectories.</p> <p>Context: Stage 0-IV; before and up to 12 months after surgery</p> <p>Setting: One regional surgical unit</p> <p>Country: Hong Kong</p> | <p>Sample size: 247</p> <p>Sampling: Convenience, consecutive</p> <p>Design: Prospective, repeated measures</p> <p>Time points: Five</p> <p>Data collection technique: Questionnaire based study; Pre-surgery baseline assessment and 4 follow-up assessments (1, 4, 8 and 12 months).</p> <p>Outcomes: Supportive care needs, five domains: health system and information; psychological; physical daily living; patient care and support; sexuality.</p> | <p>Demographic: Mean age 67.5±11.1 years; 63.6% men; 63.2% married/partnered; 41.7% at least secondary level education; 58.3% retired</p> <p>Clinical: Mean time since diagnosis 37.4±46.6 days; 47.8% colon, 39.7% rectum, 12.6% colon+rectum; 54.3% stage I-II; 80.2% laparoscopic surgery</p> | 95% |

| Author (year) | Purpose and Context | Methods | Participant Characteristics | SQS |
|----------------------------|---|--|---|-----|
| 52. Landers (2014) | <p>Purpose: To investigate patients' bowel symptom experiences and self-care strategies following sphincter-saving surgery for rectal cancer.</p> <p>Context: Six weeks to 40 months after sphincter-saving surgery</p> <p>Setting: 10 clinical sites</p> <p>Country: ROI</p> | <p>Sample size: 143</p> <p>Sampling: Convenience, consecutive</p> <p>Design: Prospective, cross-sectional</p> <p>Time points: One</p> <p>Data collection technique: Questionnaire based study; Illness Perception Questionnaire; Difficulties of Life Scale; Author-developed self-care strategies measure.</p> <p>Outcomes: Symptom experiences, self-care strategies employed</p> | <p>Demographic: 72% 60+ years old; 61.5% men; 74.1% married/partnered; 68% at least secondary level education; 53.1% retired</p> <p>Clinical: 68% 13+ months after bowel surgery; 69% good physical condition; 40% pre-surgery RT; 49% pre-surgery CT; 32% post-surgery CT.</p> | 90% |
| 53. Anderson et al. (2012) | <p>Purpose: To explore perceived patient needs for advice on diet, activity and beliefs about the role of lifestyle for reducing disease recurrence.</p> <p>Context: CRC survivors, unspecified stage</p> <p>Setting: community locations</p> <p>Country: UK</p> | <p>Sample size: 40</p> <p>Sampling: Purposive: gender, age, educational background.</p> <p>Design: Cross-sectional, qualitative focus groups</p> <p>Time points: 1</p> <p>Data collection technique: Participants were recruited by Bowel cancer UK (BCUK) in conjunction with local colorectal cancer nurse specialists</p> <p>Outcomes: dietary needs, beliefs on activity and lifestyle, the role of diet, activity and lifestyle, preferred formats, timings and routes of delivery for such guidance.</p> | <p>Demographic: 50% men, 60 yrs, BMI 26.2, 100% White British, 67% married, 57% retired, 3% smoking, 50% 1-7 alcohol units, 41% with a degree</p> <p>Clinical: 42% receiving medical treatment, Time since diagnosis: 18 months (± 11.9)</p> | 80% |
| 54. Beckjord et al. (2008) | <p>Purpose: To describe the information needs of adult cancer survivors, to identify sociodemographic, health, and healthcare-related factors associated with information needs, and to examine the relationship between information needs and survivors' perceived mental and physical health.</p> <p>Context: Cancer survivors (2-5 years in survivorship)</p> <p>Setting: n/a (secondary analysis)</p> <p>Country: USA</p> | <p>Sample size: 461</p> <p>Sampling: convenience/secondary analysis</p> <p>Design: secondary analysis combining data from two large surveys: ECHOS-NHL and APECC</p> <p>Time points: one</p> <p>Data collection technique: original survey data were collected via mailed questionnaires; in ECHOS-NHL survey mailed questionnaires or an abbreviated version by phone.</p> <p>Outcomes: Information needs, quality of care, perceived mental and physical health.</p> | <p>Demographic: Nil reported</p> <p>Clinical: Nil reported</p> | 90% |

Notes: SQS – Summary Quality Score; Studies with SQS \geq 80% are considered as the most methodologically robust.

14
15
16
17

Title Page

A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum

Grigorios Kotronoulas^{a*}, PhD, MSc, BSN, RN, Constantina Papadopoulou^b, PhD, MSc, BSN, RN, Kathryn Burns-Cunningham^c, PhD, MSc, BSc, Mhairi Simpson^d, MN, BSc, RN Roma Maguire^a, PhD, MSc, BN, RGN

^a Department of Computer and Information Sciences, University of Strathclyde, Glasgow, UK (grigorios.kotronoulas@strath.ac.uk; roma.maguire@strath.ac.uk)

^b School of Health, Nursing and Midwifery, University of the West of Scotland, Paisley, UK (constantina.papadopoulou@uws.ac.uk)

^c Dental Health Services Research Unit, Dundee Dental School, University of Dundee, Dundee, UK (k.b.cunningham@dundee.ac.uk)

^d NHS Lanarkshire, Lanarkshire, UK (Mhairi.Simpson@lanarkshire.scot.nhs.uk)

*Corresponding author:

Grigorios Kotronoulas, PhD, MSc, BSN, RN
Research Fellow
Digital Health and Well-being Group
Department of Computer and Information Sciences, University of Strathclyde
Livingstone Tower (LT14.11), 26 Richmond Street, Glasgow, G1 1XH, UK
E-mail: grigorios.kotronoulas@strath.ac.uk
Tel: +44 (0) 141 548 4101